

Alzheimer/LTC 9266
CARING FOR AMERICA'S ALZHEIMER'S VICTIMS

HEARING

BEFORE THE

**SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES**

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

MARCH 20, 1989

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CARING FOR AMERICA'S ALZHEIMER'S VICTIMS

Monday, March 20, 1989

U.S. HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON AGING,
Washington, D.C.

The committee met, pursuant to notice, at 10:10 a.m., in Room 2325, Rayburn House Office Building, Hon. Edward R. Roybal (chairman of the committee) presiding.

Members present: Representatives Roybal, Clarke, Pallone, Schuette, Slaughter, Schneider, Morella and Unsoeld.

Staff present: Manuel R. Miranda, Staff Director; Gary Christopher, Director of Health Legislation; Yvonne Santa Anna, Professional Staff; Valerie Batza, Executive Assistant; Carolyn Griffith, Staff Assistant; and Diana Jones, Staff Assistant.

OPENING STATEMENT OF CHAIRMAN EDWARD R. ROYBAL

The CHAIRMAN. The committee will come to order.

The purpose of today's hearing is to examine the problems facing Alzheimer's disease victims and their families, the progress in Alzheimer's research, the appropriate Federal role in assisting caregivers, and the need for action by the 101st Congress.

Alzheimer's research, as we all know, is grossly underfunded by the Federal Government at a time when major progress could be made in the battle against this disease. In fact, this year we will spend only \$1 in research dollars for every \$500 in Alzheimer's related societal costs.

As compared to other major diseases, Alzheimer's is not receiving its fair share of Federal dollars. This year we will spend only \$120 million on Alzheimer's research while annual societal costs may exceed \$79 billion. At the same time, we will spend 4 to 11 times that amount on research, that is \$600 million to \$1.4 billion, on each of the other major diseases. We think that that money should be spent for other major diseases but we also believe that Alzheimer's should not be ignored.

While the societal costs are great, the personal tragedies tell the story of how Federal policy has failed America's Alzheimer's victims and their families. Richard Moll, whose father was lost to Alzheimer's, will testify as to the great burden borne by him and his mother. He will also echo the national Alzheimer's Association call for expanded research and Federal assistance to family caregivers.

Enacting the CARE legislative package, we call this the Comprehensive Alzheimer's Assistance Research and Education Act (H.R. 1490), which will be introduced today by Congressman Waxman,

Stark and myself, will go a long way toward correcting the shortfall in Federal support for Alzheimer's related diseases.

However, expanded research funding is not enough. While the Roybal-Waxman-Stark CARE legislation is not a long-term care bill, CARE launches 50 or more State Alzheimer's Programs, joint Federal-State partnerships providing assistance to professional and family caregivers. Under CARE, the States receive matching funds to develop services to assist family caregivers, including the development and funding of respite care.

All of this, ladies and gentlemen, sounds very good but, you know, the bill is just being introduced. We hope it will have a hearing, we hope that it will pass the Congress of the United States. But in order for that piece of legislation or any legislation to pass this Congress or any other Congress, we need the help of every caring American, everyone who really wants this legislation to become the law of the land.

Only with the help of individuals, regardless of age, will we be able to pass this bill and other bills that are designed to benefit humanity in this country.

Again, the plight of the victims of Alzheimer's disease is our best argument of why the Federal Government must take the lead in ensuring long-term care financial and quality protection for all Americans, regardless of age, regardless of income and regardless of disability.

Ladies and gentlemen, it knows no boundaries. It doesn't care how much money one has nor the age of the individual. When Alzheimer's strikes, the victim is not the only one that suffers but the family and society as a whole. That is why it is so important that we do something in this Congress and we will, with your help.

[Material submitted for the record by The Chairman follows:]

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MANUEL R. MIRANDA, PH.D.
STAFF DIRECTOR

U.S. House of Representatives Select Committee on Aging Washington, DC 20515

Telephone: (202) 228-3375

March 20, 1989

Dear Colleague:

Over the past five years, the House Select Committee on Aging has held several very emotional hearings on Alzheimer's disease. As the Committee members listened to the tragic testimony of the witnesses, it became more and more clear that the victims of this dreaded disease need the Congress to take strong and aggressive action on their behalf.

Congress must immediately escalate the war against Alzheimer's disease and related disorders. We must move toward a major expansion of research into the causes, prevention, diagnosis and treatment of this terrible disease. We must educate the general public and expand the training of health care providers. Finally, we must reach out to the families and provide them with some additional relief from the extraordinary burden of caring for the Alzheimer's victim.

As we did in both the 100th and 101st Congresses, we call upon you to lend your support to Chairman Roybal's Comprehensive Alzheimer's Assistance, Research, and Education Act -- more appropriately known as the "CARE" bill. CARE mounts a three prong attack with its provisions on research, education and family assistance. It authorizes 1) a quadrupling of research funding (including expanded funding of research centers and establishment of off-site programs), 2) the creation of State Alzheimer's Programs (with 25-50% of the funds for respite care), 3) the expansion of the National Alzheimer's Education Program, and 4) additional Medicare and Medicaid research and demonstrations.

CARE, which will be introduced on March 20th, was developed in close partnership with the Alzheimer's Disease and Related Disorders Association (ADRDA) and has received their strongest endorsement. Over the next few months, ADRDA and its 200 chapters around the country will be mounting an all out effort to reach the Congress and get this measure passed on behalf of the 3-6 million victims of Alzheimer's disease and their caring families.

Even in these years of tight budgets, Congress needs to demonstrate that the tragedy of Alzheimer's is so special that it deserves special handling. We hope that we can count on your support.

If you are interested in being a cosponsor of the CARE bill (H.R.), contact Gary Christopherson, Yvonne Santa Anna or Carolyn Griffith at 226-3375.

Sincerely,

Edward R. Roybal

Edward R. Roybal
Chairman
Select Committee on
Aging

Henry A. Waxman
Henry A. Waxman
Chairman
Subcommittee on
Health & the
Environment, Committee
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PAUL SCHLEGEL
MINORITY STAFF DIRECTOR



March 14, 1989

Hon. Edward R. Roybal
U.S. House of Representatives
Washington, D.C. 20510

Dear Mr. Roybal:

On behalf of the families and volunteers who make up the Alzheimer's Association I would like to commend you on the introduction of the Comprehensive Alzheimer's Assistance, Research, and Education (CARE) legislation.

As you well know, the tragedy of Alzheimer's Disease is one of growing proportion, with devastating public health consequences. Today, an estimated 4 million Americans suffer from Alzheimer's Disease and related disorders. According to the Office of Technology Assessment, the number of individuals afflicted by this horrible disease could exceed 7.4 million within the next 50 years.

As a result of research sponsored by the National Institutes of Health remarkable progress has been made in understanding Alzheimer's Disease. But if we hope to find a cure or effective treatment the pace of research must be accelerated by substantially increased funding. By the same token, much more needs to be done to help ease the burden of families struggling to care for a loved one at home. Federal, State, and local resources must be brought to bear to provide the respite care, adult day care, and other services families so desperately need.

The CARE bill you have introduced will go a long way towards meeting the enormous challenge presented by Alzheimer's Disease. Our Association, through its nearly 200 chapters and 1,500 community-based support groups is urging Members of Congress to join as co-sponsors of the CARE bill and to work for its passage as quickly as possible.

Thank you for the leadership role you have taken on this critically important issue.

Sincerely,

Edward F. Truschke
Edward F. Truschke
President

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOC. INC.

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101st CONGRESS

REPRESENTATIVES EDWARD R. ROYBAL,
HENRY A. WAXMAN, AND
FORTNEY (PETE) H. STARK

SUMMARY OF H.R. 1490
COMPREHENSIVE ALZHEIMER'S ASSISTANCE, RESEARCH, AND EDUCATION ACT
(CARE)

PURPOSE

To provide expanded research on Alzheimer's disease and related disorders and to improve care and assistance for its victims and their family caregivers.

BACKGROUND

Alzheimer's disease is one of a number of degenerative neurological disorders that affect over 3 million middle age and elderly individuals. The symptoms of Alzheimer's disease and these related disorders (AD) include debilitating changes in personality, memory deterioration, disorientation, and impaired impulse control and judgment. As the disease progresses, changes in intellectual functioning take place with even more severe changes. Victims may wander, develop erratic moods, become difficult to manage and become incontinent. The disease eventually renders its victims helpless and the family caregivers financially and emotionally exhausted.

To date, the federally funded research effort has been grossly underfunded as compared to federal funding for the other major diseases. While Alzheimer's related funding total about \$120 million annually, funding for heart disease, AIDS and cancer research each total between \$600 million and \$1.45 billion annually. This discrepancy occurs in spite of the fact that the social and economic costs of Alzheimer's are on the same order of magnitude (or greater) as these major diseases. Further, our current federal research spending amounts to only about \$1 in annual research expenditures for every \$500 in annual societal costs. Over three years, this CARE bill proposes to quadruple federal research funding — totaling \$500 million by 1992 — for Alzheimer's and related disorders.

Although Congress has directed much research toward Alzheimer's Disease and related disorders, inadequate dissemination of information to the medical community and the public has resulted in misdiagnosis and lack of access to treatment management options for many patients. In addition, the nature of these disorders has left families with an extreme psychological, physical and economic burden that warrants a systematic examination of models of care and reimbursement policies. Moreover, recent critical research breakthroughs relative to causes of and treatment for Alzheimer's Disease and related disorders make it apparent that the research, treatment and management of these disorders have reached a point where a coordinated effort, including the states, the federal government and private groups, is warranted.

Beyond research, there is a great need to provide support to the Alzheimer's victims and their caregivers. Currently, Medicaid is one of the few programs providing support, but only after the individual and their families face virtual impoverishment. While long term care will be addressed in other legislation, the federal government should move quickly in a joint effort with the States to develop a state-based support system for Alzheimer's victims and their caregivers. For 1992, the CARE bill proposes \$125 million in funding for State Alzheimer's Programs, a joint federal-state partnership, to provide the core of that support system.

**COMPREHENSIVE ALZHEIMER'S ASSISTANCE,
RESEARCH AND EDUCATION ACT (CARE)**

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CARE BILL SUMMARY

Responding to the overwhelming need to assist the victims of Alzheimer's disease and related disorders, the CARE legislative package, developed in partnership with the Alzheimer's Association and on behalf of its more than 200 Chapters nationwide, proposes the following initiatives:

- * Over a three year phase-in, provides for a quadrupling of Alzheimer's related biomedical research funding to a level of \$500 million by 1992 including funding for drug and genetic research.
- * From that research funding, a total of 15 AD research centers are to be fully funded and a new program of off-site research on diagnosis and treatment is to be initiated.
- * Funds research on services to promote the health and well-being of AD victims and their families by encouraging care in the home and reducing the stress on the families.
- * Expands funding for the National Alzheimer's Education Program.
- * Creates state programs with education and supportive services, including respite care, for AD victims. Provides a phase-in of funding reaching \$90 million/year by 1992.
- * Modifies Medicare and Medicaid to better support AD victims and families.
- * Funds Medicare and Medicaid research to examine potential changes in eligibility, benefits and reimbursement.
- * Increases training of health care providers for AD victims and families.
- * Modifies the Alcohol, Drug Abuse and Mental Health Block Grant to better support AD victims and families.
- * Requires that Secretary coordinate Alzheimer's related research of Department of Health and Human Services.

CARE BILL PROVISIONS

TITLE I. PUBLIC HEALTH SERVICE PROGRAMS WITH RESPECT TO ALZHEIMER'S DISEASE.

Sections 901-902. BIOMEDICAL RESEARCH ON ALZHEIMER'S DISEASE AND RELATED DISORDERS.

Requires that the Department of Health and Human Services develop a plan of AD related research and implement it through the National Institutes of Health (NIH) (including the National Institute on Aging (NIA)) and the National Institute of Mental Health (NIMH).

- * Expands NIH and NIMH biomedical research programs by funding basic research related to AD at a combined level of \$225 million for 1990, \$400 million for 1991, and \$500 million for 1992. Of the total biomedical research funding, 80 percent goes to NIH, 10 percent goes to NIMH, and 10 percent is to be distributed between NIH and NIMH according to priorities developed by the DHHS Secretary.

COMPREHENSIVE ALZHEIMER'S ASSISTANCE, RESEARCH AND EDUCATION ACT (CARE)

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- * From the above NIH and NIMH research funding and subject to the level of the total appropriation for this research, research priorities include the etiology of AD (minimum of \$25 million per year), the epidemiology of AD (minimum of \$15 million per year, diagnosis of AD (minimum of \$10 million per year), the treatment and management of AD (minimum of \$20 million per year) and the burden of caring for AD victims (minimum of \$10 million per year).
- * From the above NIH and NIMH research funding, the current Centers program is extended by fully funding 15 Alzheimer's Research Centers at a level of \$25 million in 1990, \$32 million in 1991 and \$40 million in 1992. In addition, this funding also provides funding for a new initiative to develop off-site research on diagnosis and treatment of AD with authorized funding of \$15 million in 1990, \$17 million in 1991 and \$20 million in 1992. The Centers and the off-site programs are to be administered by the National Institute on Aging in collaboration with NIMH, NINCDS and NIAID. Responsibilities of the Centers include:
 - Conducting research into cause, prevention, diagnosis, treatment and management of AD;
 - Training health care personnel;
 - Disseminating clinical information;
 - Conducting community education on AD;
 - Coordinating with other Centers and related public/private facilities.
- * Provides for coordination and dissemination of research both within DHHS and to other relevant agencies.

Sections 903-906. FAMILY SUPPORT AND SERVICE DELIVERY RESEARCH AND DEMONSTRATIONS.

Establishes research and demonstration programs to develop methods of service delivery that will promote the health and well-being of AD victims and their families by encouraging care in the home and reducing the stress on the families of AD patients.

- * NIMH Family Support and Stress Research: Authorizes \$25 million in 1990, \$26 million in 1991 and \$28 million in 1992 to support joint research and demonstration projects with public and private organizations.
- * NIA Long Term Care Research: Authorizes \$12 million in 1990, \$12.5 million in 1991 and \$13 million in 1992 to support long term care research on Alzheimer's Disease and related disorders and on the coordination of long term care.
- * National Center for Health Services Research Model Delivery Systems Research: Authorizes \$5 million in 1990, \$6 million in 1991 and \$7 million in 1992 to conduct research on models for improving the delivery of supportive services to AD patients and their families, with particular attention to ethnic and cultural groups.
- * Administration on Aging Family Support Demonstrations: Authorizes \$12 million in 1990, \$12.5 million in 1991 and \$13 million in 1992 to support joint demonstration projects with public and private organizations examining innovative family support and service delivery approaches with special emphasis on stress inducing disorders such as AD.

Section 908. DEPARTMENT COORDINATION OF ALZHEIMER'S RELATED RESEARCH. Requires that the Secretary of the Department of Health and Human Services establish a mechanism to coordinate all Alzheimer's related research within the Department.

**COMPREHENSIVE ALZHEIMER'S ASSISTANCE,
RESEARCH AND EDUCATION ACT (CARE)**

Section 921. STATE ALZHEIMER'S PROGRAMS. Establishes a joint federal and state effort to develop services and policies to assist victims of AD and their families. All 50 States and territories may receive grants to create State Alzheimer's Programs.

- * Develops diagnostic, treatment, care management, legal counseling, and educational services for care providers, victims, and their families.
- * Makes available respite care services (including, but not limited to, home health, day care, companion, short term stay in health facilities) for the AD patient. (Between 25% and 50% of the grant is to be used for this purpose.)
- * Reviews state policies on the financing and reimbursement of the costs of health care for patients with AD and identifies other policy changes that would improve the care of patients with AD.
- * Disseminates information to victims, their families, health care providers, organizations established for patients with AD and to the general public on services available to AD victims as well as on rights of and sources of assistance for AD victims and their families.
- * Makes initial grants available for 3 years with funding at a minimum of \$250,000 per year and subject to an annual evaluation by the Department of Health and Human Services.
- * States are required to provide matching funds at a 50-50 rate.
- * Total program funding is set at \$50 million for 1990, \$100 million for 1991, and \$125 million for 1992.

Section 931. ACCESS TO COMMUNITY MENTAL HEALTH CENTERS. Improves access to Community Mental Health Centers by the elderly and by AD victims and their families.

- * Directs the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) to require that Community Mental Health Centers (CMHCs) receiving ADAMHA Block Grant funds increase their efforts to reach the elderly and to reach AD victims and their families. Authorizes an additional \$50 million in 1990, \$52 million in 1991 and \$55 million in 1992.
 - CMHCs provide increased services and outreach to the elderly and to AD victims and their families
 - CMHCs report annually to ADAMHA on their services and outreach for the elderly and for AD victims and their families.

Sections 941-942. TRAINING OF HEALTH PROFESSIONALS AND RESEARCH ON MANPOWER.

Increases training of health care professionals and paraprofessionals to improve the diagnosis, treatment and management of AD.

- * Provides NIA Grants to medical, psychology, nursing, social work, gerontology, and health administration schools and to AD research centers for training and continuing education on health and long term care using AD as an illustrative case. Grants shall be awarded so as to ensure appropriate geographic coverage. Authorizes \$10 million in 1990, \$10.5 million in 1991 and \$11 million in 1992.

**COMPREHENSIVE ALZHEIMER'S ASSISTANCE,
RESEARCH AND EDUCATION ACT (CARE)**

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- * Provides NIA Grants to AD Research Centers to assist schools in developing curricula for training and continuing education and to ensure transfer of the most up-to-date research information. Authorizes \$2 million in 1990, \$2 million in 1991 and \$2 million in 1992.
- * Requires that the Health Resources and Services Administration (HRSA) conduct a manpower study to determine the adequacy of health manpower for meeting the ongoing care needs of AD and other long term care patients as well as the adequacy of training, of geographic distribution by discipline, and of minority and ethnic personnel and to determine mechanisms for coordinating its manpower efforts with those of other relevant federal agencies. Authorizes \$200,000 per year.

Sections 951-952. NATIONAL ALZHEIMER'S EDUCATION PROGRAM AND CAREGIVER EDUCATION.

Expands funding for the National Alzheimer's Education Program, a national program (similar to the successful National High Blood Pressure Education Program), which was already established in the Department of Health and Human Services annual Appropriations bills and is administered through the National Institute on Aging, to create a national focus on the problem of AD and the care of its victims.

- * Brings together public and private organizations to develop better ways to provide care to AD patients and assist their families.
- * Provides technical assistance to public and private organizations delivering services to AD patients and providing information (including the rights of and sources of assistance for AD victims and their families) to the public and health care providers.
- * Incorporates the Clearinghouse on Alzheimer's Disease which collects information from research and treatment programs and makes this information available to victims of AD and their families, to health care professionals and to the general public.
- * Fosters and coordinates research, training, and education programs relating to AD cause, treatment and diagnosis.
- * Funding is set at \$2.0 million for 1990, \$2.5 million for 1991, and \$3 million for 1992.

Provides NIA Grants to public and private non-profit organizations to fund training programs for direct care providers and family caregivers on what public and private resources are available to AD victims and their family caregivers and on how best to provide care to AD victims. Grants shall be awarded so as to ensure appropriate geographic coverage. Authorizes \$10 million in 1990, \$10.5 million in 1991 and \$11 million in 1991.

TITLE II. IMPROVEMENT OF SERVICES UNDER MEDICARE AND MEDICAID.**Sections 201-203. MEDICARE AND MEDICAID PROGRAM MODIFICATIONS AND RESEARCH AND DEMONSTRATION PROJECTS.**

Improves Medicare and Medicaid access, quality and reimbursement with respect to Medicare and Medicaid covered AD victims.

- * Directs the Health Care Financing Administration (HCFA) to modify the Medicare and Medicaid programs to:
 - review and, as needed, modify reimbursement for home health services, extended care services and inpatient hospital services to reflect more accurately the cost of caring for advanced stages of AD;
 - upgrade quality of care and utilization reviews for heavy care patients such as AD patients;
 - ensure that access to nursing home and home health care for AD victims is not limited by the practices of nursing home and home health agencies.

Mandates that the Department of Health and Human Services continue to conduct AD related research, demonstrations, and waiver projects in order for Medicare and Medicaid to better assist AD victims. Projects include at least the following:

- * Provision of community-based care (including day care) and in-home care, as well as improved nursing home and home health staffing and training.
- * Provision of alternative methods of health care delivery systems for AD patients, including services designed to maintain patients in the home.
- * Alternative methods of payment for long term care (including home health care and nursing facility services) for AD and other heavy care patients.
- * Coverage of nursing home care without the need for skilled nursing care. (Current reimbursement policy precludes reimbursement by Medicare until medical management of the condition is warranted and unless nursing home and home health care are skilled. It precludes reimbursement by Medicaid until the victim's resources are depleted and until the community spouse's resources are spent down to the new standards under the Medicare Catastrophic Coverage Act.)
- * Funding for administrative costs relating to research and demonstration projects is set at \$6.0 million for 1990, \$7.0 million for 1991, and \$8.0 million for 1992.

NOTE: While the CARE legislative package addresses the Alzheimer's problem directly, Congressman Roybal has introduced several other bills which also address the needs of Alzheimer's victims and their families. The "USHealth Program Act" (H.R. 200) is a broad health care reform package which would provide health and long term care protection for all Alzheimer's victims.

The CHAIRMAN. The Chair now recognizes and would like to welcome Mr. Frank Pallone Jr. of New Jersey who is a new member of the committee. When he was campaigning for election, he wanted to be sure that he was placed on this committee. We did everything that we could to comply because of his background in this field.

I am not going to recite his credentials but I would like to ask him at this time if he will address those that are gathered here for just a few minutes. Will you proceed, Mr. Pallone?

STATEMENT OF REPRESENTATIVE FRANK PALLONE, JR

Mr. PALLONE. Thank you, Mr. Chairman. I do appreciate what you said. I certainly am very pleased to be a member of the committee and appreciate your support in helping me to become a member of the committee.

I think that today's hearing and the legislation that you have introduced more than makes the point as to why this is such an important committee, not only for myself but our constituents nationwide.

Alzheimer's and related disorders is a major concern in my district because of the large senior citizen community but it is also an issue among younger people who have to care for Alzheimer's victims.

One of the things that I was particularly pleased to see today is that the CARE legislation talks about State matching programs that relate to both respite care as well as day care because I personally have been mostly involved on a State level, as a State Legislator, dealing with day care concerns.

In New Jersey, we do have some day care programs many of which I have visited. There is no doubt that the need for day care programs is tremendous and that this is one of the major concerns of those who have to care for Alzheimer's victims. Day care options are a way for the caretakers to keep their parents, their relatives at home as long as possible. In fact while they are working during the week, they can send their parent or the person they are taking care of to a day care center.

I've seen some wonderful day care centers, and I hope that through this legislation or other legislation that the committee may be looking at over the next 2 years, that we can promote the option of adult day care, particularly for Alzheimer's victims, as much as possible.

It seems to me that the amount of time, or the fact that the committee is starting with this legislation today, really shows the commitment of not only you, Mr. Chairman, but the entire Aging Committee, to Alzheimer's concerns. Thank you.

The CHAIRMAN. Thank you. The Chair now recognizes Ms. Slaughter.

STATEMENT OF REPRESENTATIVE LOUISE M. SLAUGHTER

Ms. SLAUGHTER. Thank you, Mr. Chairman. I first want to say how pleased I am to again be a member of the Select Committee on Aging and I look forward to another 2 years of work on issues that effect our senior population.

But before I begin my statement, I would like to give a special welcome to one of today's witnesses, Dr. T. Franklin Williams. He is head of the National Institute of Aging and he is recognized throughout the world as an expert in the field of geriatrics but he is someone that I also consider a friend.

Dr. Williams came to Washington from Rochester, New York, where we miss him still. He was the Medical Director of the Community Hospital there and pioneered geriatric studies. He developed an evaluation clinic that is the predecessor of models that are now used throughout the country. Our loss is Washington's gain and the country's gain. Welcome, Franklin.

Mr. Chairman, thank you for holding this important hearing. Alzheimer's disease and the related disorders afflict over 3,000,000 men and women in this country. It is one of the most feared and dreaded diseases that face the Nation's senior citizens. The research community has come very close to unlocking the mysteries of Alzheimer's disease.

The scientific community has encouraging news, that we may begin to understand the biological causes very soon. Even with these breakthroughs, it is little consolation to the over 3,000,000 that suffer dementia disorders today.

The strain on these older Americans must be unbearable and the strain and stress that the disease causes their families and those who care for them must be even worse. Physical and psychological demands of the disease requires us to focus greater attention and support on research both for the patient and for the caregivers.

I am proud to report that a program in my district, the Monroe Community Long-term Care Program, has recently been selected as one of eight national Medicare Alzheimer's disease demonstration models. One of the major goals of the project is to determine the impact of expanded community based services to the patients and to their families and see if the services will delay or prevent institutionalization of Alzheimer's patients.

I believe we learn much from demonstration programs such as Rochester's and that other research programs into Alzheimer's will help us shape an overall policy for long-term care.

Because of the nature of the disease, those with dementia require care for an average of 10 years or longer, far greater than for other diseases. Research about the patient and the caregiver can give a significant insight into the way we think about providing long-term care in America.

This is significant not only for its policy considerations, but is important during the days of tight budgets when we are competing for scarce research dollars. By the year 2000, the number of victims with dementia is expected to increase by 60 percent and as we move further into the new century, the growth of the aging population will increase in numbers of people who are at risk.

The struggle to find a cure for Alzheimer's will continue, but until the time that we find the cure we must look to alleviate the enormous burden that this disease places on those who suffer from Alzheimer's and those who care for them. Mr. Chairman, I welcome the testimony from today's panelist to help guide us in that direction.

The CHAIRMAN. Thank you, Ms. Slaughter. At this time, if there are no objections, I would like to submit the prepared statements of several of our colleagues for the hearing record. Hearing no objection, so ordered.

[The prepared statements of Representatives Thomas J. Downey, Constance A. Morella, Ralph Regula, Olympia J. Snowe, and Jim Lightfoot follow:]

PREPARED STATEMENT OF REPRESENTATIVE THOMAS J. DOWNEY

I would like to commend Chairman Roybal for calling this hearing today on the plight of Alzheimer's patients and the extreme hardships faced by their families as well as the progress that is being made in Alzheimer's research.

As the Chairman of the Subcommittee on Human Services, I strongly support additional funding for Alzheimer's research. I have joined Chairman Roybal as an original co-sponsor of the legislation he is introducing today, H.R. 1490, the Comprehensive Alzheimer's Assistance, Research and Education Act, otherwise known as the "CARE" bill. I will work for its passage because it will provide a stronger Federal commitment to the victims of Alzheimer's disease and the family members who care for them.

In June of 1986 I chaired a field hearing of the Select Committee on Aging in which I learned firsthand of the experiences of Long Island families affected by Alzheimer's disease. I believe we must have a two pronged approach to dealing with the devastating Alzheimer's tragedy: one, more research and training and two, better care and treatment not only for the victims but also for those who bear the burden of caring for them. H.R. 1490 proposes to increase Federal research funding fourfold, bringing the total to \$500 million by the year 1992. In addition, the CARE bill proposes \$125 million in funding for state Alzheimer programs, which will provide for a joint effort between the states and the Federal government to bring much needed respite for Alzheimer's caregivers.

The Subcommittee on Human Services has oversight responsibility over the Older Americans Act, which has been our nation's most effective program for providing social and human services for the elderly for over two decades. I am proud to say that the 1987 Amendments to the Act contained a new provision, TITLE III D, Non Medical In Home Services for the Frail Elderly, which includes first time funding for programs that provide services to victims of Alzheimer's disease and their families. This first time funding of \$7.4 million is certainly significant, but this amount must be substantially increased if we are to cope with the growing cost of Alzheimer's disease. It is my intention to seek additional funds for this provision when I appear before the Subcommittee on Labor, Health and Human Services and Education in late April.

I appreciate the opportunity this hearing offers, and I look forward to our witnesses' testimony.

PREPARED STATEMENT OF REPRESENTATIVE CONSTANCE A. MORELLA

MR. CHAIRMAN, THANK YOU FOR CALLING THIS HEARING TODAY TO EXAMINE THE PROBLEMS FACING ALZHEIMER'S DISEASE VICTIMS AND THEIR FAMILIES AND THE PROGRESS BEING MADE IN ALZHEIMER'S DISEASE RESEARCH. IT IS CLEAR THAT CONGRESS MUST EXPAND FEDERAL SUPPORT FOR RESEARCH EFFORTS TO PREVENT, TREAT, AND CURE THIS DEVASTATING DISEASE.

I AM PLEASED TO AGAIN BE A COSPONSOR OF YOUR LEGISLATION, THE COMPREHENSIVE ALZHEIMER'S ASSISTANCE, RESEARCH, AND EDUCATION ACT, THE "CARE" BILL. ITS THREE PRONG FOCUS ON RESEARCH, EDUCATION, AND FAMILY ASSISTANCE WOULD GO A LONG WAY TOWARD ACHIEVING OUR RESEARCH OBJECTIVES, EDUCATING THE PUBLIC, AND PROVIDING RELIEF TO THE FAMILIES OF ALZHEIMER'S VICTIMS.

I HOPE THAT THE HEARING TODAY WILL HELP TO FURTHER CLARIFY CURRENT PRIORITIES, AND WILL ASSIST US IN DEVELOPING SOLUTIONS TO ADDRESS THESE PROBLEMS. I LOOK FORWARD TO HEARING FROM THE DISTINGUISHED WITNESSES WHO ARE WITH US TODAY, AND TO PARTICIPATING IN THIS URGENT DISCUSSION.

 PREPARED STATEMENT OF REPRESENTATIVE RALPH REGULA

Mr. Chairman:

I commend you for your leadership in calling this important hearing. The subject of today's session, Alzheimer's Disease, is one of great concern to our nation's elderly and to the nation as a whole.

While this disorder was first diagnosed in 1906, it is only within the last decade that we have become knowledgeable about the disease and the hardship it causes for the afflicted, as well as for their families and friends. It is estimated that over 3 million persons are afflicted by this disorder and more than 50% of nursing home admissions are by persons exhibiting symptoms of the disease. It is the fourth leading cause of death for the elderly and it's complications kill over one hundred thousand people annually.

We have accomplished a great deal within the last several years. For example, members of this committee joined Congressman Pepper and myself in sponsoring legislation creating 8 national Alzheimer's Disease centers. These centers will do much toward establishing a national treatment policy. Patient treatment began in February of this year.

Despite such efforts much remains to be done. Severe problems exist in the case management of these people. We still do not have a reimbursement system that prevents the impoverishment of these patients before they can be eligible for adequate care. And finally, every effort must be taken to improve support systems for the patient and his caregiver.

Since the care of these patients is largely "custodial" the only public program providing coverage is Medicaid. Medicare does not currently reimburse for such services. However, the recently enacted catastrophic law will enable the spouses of these patients to retain a certain level of personal assets and still qualify for the Medicaid program.

For these reasons, I look forward to hearing the testimony of the expert witnesses assembled here today. I am confident their comments will provide an insight into the difficult problem of caring for Alzheimer patients.

OPENING STATEMENT OF REPRESENTATIVE OLYMPIA J. SNOWE

Mr. Chairman, I want to commend you for holding this important hearing today which examines the impact of Alzheimer's disease on individuals afflicted with the illness and their families, and which underscores the need for both expanded federal Alzheimer's research and assistance for those providing informal care.

I have long had a special concern for Alzheimer's victims and their caregiving families. As you know, in most cases of Alzheimer's disease, the families bear the brunt of the responsibility for care. A study published by the Subcommittee on Human Services, of which I am the Ranking Minority Member, concluded that families provide 80 percent of the needed care for chronically ill family members. Family care is an integral factor in preventing or delaying institutional care.

However, continued family caregiving comes at a very high price. This is especially significant in caring for individuals with Alzheimer's disease because the diminished mental capacities associated with the disease require that the individual receive constant supervision.

It is because of my special concern for the two victims of Alzheimer's disease -- the patient and the family -- that I

have made a strong commitment to Alzheimer's research and family caregiving. I am very pleased that legislation that I introduced in the 99th Congress to coordinate federal Alzheimer's research was included in the Victims Compensation Act, PL 99-660. This measure established a national Alzheimer's disease clearinghouse and provided for research on the needs of caregivers.

At present, the Department of Health and Human Services Advisory Committee on Alzheimer's disease, established by PL 99-660, is completing a report on the biomedical advances in Alzheimer's disease. Following the publication of this report, I will sponsor a forum which will enable Members of Congress and concerned individuals to learn about recent biomedical advances.

Because of my ongoing concern about the need to assist family caregivers with the pressures of supporting victims of Alzheimer's disease, I have introduced legislation which would provide tax deductions from gross income for individual taxpayers who maintain a household which includes a dependent who has Alzheimer's disease or a related disorder. This measure, H.R. 550, would allow deductions of non-medical expenses which are related to the home health care, adult day care, and in-home respite care of the Alzheimer's victim.

Further, I have sponsored a measure, H.R. 1272, which amends the Domestic Service Volunteer Act to establish respite services as a priority category for the Retired Senior Volunteer Program (RSVP). Although RSVP volunteers are currently providing respite care services, H.R. 1272 would allow RSVP directors to further target resources towards this very important area. Services such as respite care provide informal caregivers with a break from their caregiving responsibilities. Such support services can be a crucial factor in continued caregiving activities.

In recognition of the outstanding contribution of family caregivers in keeping their frail and disabled family members at home, I have introduced legislation, which has been signed into law by the President for the past three years, that establishes the week of Thanksgiving as "National Family Caregivers Week". During this week, organizations across the nation carry on activities that let caregivers know the extent of our support and our indebtedness to them.

As families attempt to cope with the needs of dependent Alzheimer's victims, we must target resources not only towards the ill individual, but also towards assisting those who shoulder the burden of their care.

Mr. Chairman, I again wish to extend to you my sincere appreciation for holding this important hearing. I look forward to hearing the statements of those testifying today.

PREPARED STATEMENT OF REPRESENTATIVE JIM LIGHTFOOT

MR. CHAIRMAN, I WANT TO THANK YOU FOR HOLDING THIS HEARING ON AN IMPORTANT TOPIC THAT AFFECTS MILLION OF ADULTS AND THEIR LOVED ONES - ALZHEIMER'S DISEASE. I LOOK FORWARD TO RECEIVING TESTIMONY FROM OUR DISTINGUISHED PANELISTS AND WELCOME THEIR INPUT AND SUGGESTIONS TO LESSEN THE ANGUISH EXPERIENCED BY INDIVIDUALS SUFFERING FROM ALZHEIMER'S DISEASE.

MR. CHAIRMAN, AN ESTIMATED 33,000 IOWANS SUFFER FROM ALZHEIMER'S OR RELATED DISORDERS. THE STATE OF IOWA'S POPULATION CONSISTS OF A LARGE NUMBER OF OLDER AMERICANS OVER THE AGE OF 65. IN FACT, IOWA RANKS FIRST IN THE PERCENTAGE OF POPULATION OVER 85 YEARS OF AGE.

RURAL ELDERLY SUFFERING FROM ALZHEIMER'S DISEASE EXPERIENCE DIFFERENT PROBLEMS FROM THEIR URBAN COUNTERPARTS. IN MANY CASES THESE INDIVIDUALS LACK THE NECESSARY MEDICAL AND SOCIAL SERVICES READILY AVAILABLE IN URBAN AREAS. IN THE EARLY STAGES, AN ALZHEIMER'S PATIENT REQUIRES LITTLE SUPERVISION OR SUPPORT AND HIS OR HER NEEDS CAN BE EASILY MET AT HOME. BUT THE DISEASE PROGRESSES AND THE NEED FOR RESPITE CARE SERVICES OR EVEN LONG-TERM HEALTH CARE SERVICES IS IMMINENT. STUDIES INDICATE THAT ALTHOUGH HOME CARE IS ECONOMICALLY PREFERABLE, SUCH SERVICES HAVE NOT BEEN DEVELOPED FULLY IN RURAL AREAS THEREBY LEAVING INSTITUTIONALIZATION AS THE ONLY ALTERNATIVE FOR CARE.

ALZHEIMER'S DISEASE IS A FRUSTRATING DISEASE FOR FAMILIES, DOCTORS, AND THE INDIVIDUAL SUFFERER. NEW DRUGS ARE CONSTANTLY BEING RESEARCHED, AND A GREAT DEAL OF TIME AND EFFORT IS DEVOTED TO STUDYING ALZHEIMER'S BY THE DEPARTMENT OF HEALTH AND HUMAN RESOURCES. WITH CONTINUED RESEARCH AND STUDY, THE MYSTERY OF THIS DEADLY AND DEBILITATING DISEASE WILL BE UNRAVELED.

THANK YOU AGAIN MR. CHAIRMAN FOR HOLDING THIS HEARING.

The CHAIRMAN. The Chair is now pleased to introduce four very important witnesses. The first is Ms. Nancy Lombardo, who is Vice Chairman of the Public Policy Committee of the National Alzheimer's Association. Her mother is a victim of the disease and has been for 23 years. Ms. Lombardo lives in the State of Michigan.

Our next witness is someone we all know. He is a little guy and we like him. He is Richard Moll, a well known actor in television's Night Court comedy series. He is with us today because his father was stricken with Alzheimer's. For many years before his father's death, Mr. Moll's mother and his family cared for their father.

Mr. Moll comes from the State of California and represents the Los Angeles Chapter of the Alzheimer's Association.

The next witness is Frank DeLay, the National Board Member of the American Association of Retired Persons, and is from Mesa, Arizona. Mr. DeLay will be speaking on AARP's position on the need for long-term care and how Alzheimer's makes a clear case for a national long-term policy.

Our final witness is an old friend, a gentleman who always answers our call for help. When this committee needs expert testimony of any kind, he is ready to comply. He is the representative of the Department of Health and Human Services. He will focus his testimony on where we stand today with respect to Alzheimer's research and the need for funding. Dr. Franklin Williams is the Director of the National Institute on Aging.

The Chair will recognize first Ms. Nancy Lombardo.

STATEMENT OF NANCY LOMBARDO, MEMBER, BOARD OF DIRECTORS, DETROIT CHAPTER, ALZHEIMER'S ASSOCIATION; AND VICE CHAIRMAN, NATIONAL BOARD OF DIRECTORS, ALZHEIMER'S ASSOCIATION

Ms. LOMBARDO. I am very pleased to be here today, Mr. Chairman. I am active in the Alzheimer's Association and have been for 9 years. I am in Michigan now and on the Board of Directors of the Detroit Chapter, which I helped found in 1981. I am also Vice Chair of our national board of directors and chair of the association's public policy committee.

Like most of us in the association, it is a personal experience that brings me here today. As you mentioned a few minutes ago, Mr. Chairman, my mother has been a victim of Alzheimer's disease for 23 years.

I remember when she was first diagnosed, my father, who is a doctor, tried to find out about Alzheimer's disease. Even though he is a doctor and went to a good medical school library, Albany Medical School, all he could find was a very short chapter in a book, about 7 pages long. It was mainly about the pathology of the brain; it gave him no guidance as to what to expect. It said the average life expectancy was 5 to 7 years, and he began to face this terrible illness alone, with only his family around him.

I happened to be home when we learned of my mother's illness. I got married at the time my mother became ill so I was not the principal caregiver. I provided respite care when my dad needed to attend a medical meeting. But I still remember that I happened to be home when he came home one day from the VA, where he was

a physician. He had talked to a gentleman in his 80's and learned that this gentleman had been taking care of his wife with Alzheimer's for 20 years. My father fell apart. He just couldn't imagine dealing with this illness that many years, and now he's doing it.

It is a long-term care problem. Whether someone is dealing with this disease for 3 or 5 years or 10, 15 or 20, it is really a very long haul.

Like many others in the association, I know we can't stop my mother's own illness. She is too far along. Even if we found a cure tomorrow, it would not help her. But I think I and everyone in this room can do something about the future, to get the research we need, to find if this disease is curable or preventable and stop this disease for the future generations, my children, myself, my friends, and my colleagues. None of us really want to face this disease ourselves and we certainly want to do everything we can to prevent it. We are also driven to help the other families that must now cope with this disease.

It is just amazing now the amount of information available, compared to virtually nothing 20 years ago, whether it is through books on Alzheimer's disease or family support stories. It is just incredible how much more we know than was available to my family 20 years ago. Every one of the nearly 200 chapters in our association is able to provide families with information and personal help and this is what we are all about. As I mentioned, we now have nearly 200 chapters around the country, 1,500 to 2,000 family support groups and at least 30,000 volunteers.

There is strong evidence to suggest that as many as 4 million Americans suffer from Alzheimer's disease, including those in the early and middle stages. That is nearly double what the OTA report estimated for severely demented people alone. As a result, some estimate that this disease and the related disorders, may affect 15 percent of those over 65 and as many as 40 to 50 percent of those over age 85.

Chairman Roybal, before I go any further, I want to thank you personally for the leadership that you have shown on this issue. When people were just beginning to learn what the term Alzheimer's disease meant, you knew all about it from your earlier work, 20 or 30 years ago. You were always our shining light of hope when few people were willing to take leadership on this issue and I want to thank you for everything that you have done, each and every year that you have helped introduce legislation.

Once again, you have introduced one of the most comprehensive bills on this subject. It shows your understanding of the many, many complexities of this problem and points out that our present health system is simply not equipped to deal with the unique problems of dementia patients.

The demographic shifts that Congresswoman Slaughter talked about are really going to make this disease even more important for the future than it is already. As a Nation, we have to take actions now, through research to prevent this disease, through services to help families, and a long-term care system to help avoid the catastrophic costs of caring for Alzheimer patients and to eliminate the crisis that families face when they become financially devastat-

ed after facing the emotional and physical problems that this disease represents.

We are so happy that you are calling for \$500 million in research monies by 1992. Coincidentally, that is the target that the association has set. We feel that \$30 a patient, which is the current rate of spending for research, when caring for a patient for 1 year can be \$20,000 to \$25,000, just doesn't make sense. It is poor economics. We need a much greater investment. There have been many, many promising research leads and if we make a national commitment to a war on Alzheimer's disease similar to the war on cancer a decade ago, I know we can make an impact.

We also need to look at the care needs of people that are currently suffering from the disease. As you know, 70 or 80 percent of patients are cared for at home. In fact, some studies show that at least 40 percent of patients die at home without ever being institutionalized, so in many cases the families are able to take care of them. But these families need help and support. They cannot do this alone.

There are some innovative respite and adult day care programs around the country but they are really small programs and in scattered areas. We need much more of that. We need much more training for not only professional providers that help take care of our patients, but for the families so they can do a better job of caring for their patient at home.

Then when for many families nursing home placement does become a necessity, we need those nursing homes better equipped to take care of dementia patients. We need their staff well trained, we need the environments of a nursing home properly attuned to their needs. All of these areas are things that your bill looks at. In short, we need reconstruction of the Medicare and Medicaid systems.

As you know, our association joined others in supporting the Pepper/Roybal bill, which was an effort to get home care coverage under the Medicare program. We were disappointed when it went down to defeat but we look confidently to the future that comprehensive long-term care legislation will pass in the next couple of years.

We are members of the long-term care campaign and join with other organizations and families working with other disabilities. This, along with research, is one of our top priorities. We welcome your support and are delighted that Mr. Waxman and Mr. Stark also are cosponsoring this legislation.

We are hoping that any long-term care legislation that is enacted will be based on social insurance principles and cover all ages and incomes and not just those over 65. Since many of our patients are under 65, we hope that the legislation will look at the special care needs of dementia patients.

Since they are such a huge percentage of the long-term population, the eligibility criteria must take them into account. We need specialized education and training for all of the providers involved, a broad benefit package that meets all of the care needs of Alzheimer's patients, and cost-sharing so that no family goes down to economic bankruptcy from this disease.

Finally, it is so important that your bill supports the here-and-now service needs of families and patients. It lays the foundation for a solid partnership of the private sector, such as our volunteer association, State governments and the Federal Government.

Just to acquaint you with our chapter network, we have, as I said, almost 200 chapters. They all have 24-hour hot lines, they have newsletters, our national association has a newsletter. We reach probably 1,000,000 people this way.

Anyone that needs help can call our chapters or our national toll-free number, 800-621-0379, and get referrals to services. They can become part of a support group and get personal attention, not bureaucratic referrals. It is very important to have this person-to-person contact available. Furthermore, many of our chapters are getting into counseling case management and respite care and day care.

Meanwhile, the State governments and the Federal Government can inspire State level programs. According to our surveys over 40 States already have some kind of Alzheimer's specific program, whether it is a very small start, like a task force, or training and education program, or comprehensive programs with a variety of services.

At least 40 States are already investing money, whether it's \$10,000 or several million, such as in California, Florida, Ohio and Illinois. The most popular seem to be education and training programs, respite and day care, research and diagnostic and assessment programs.

I think the stimulus of having some Federal guidance and the attractiveness of a matching program would help the State level programs take off, so I look to your legislation as a cornerstone. The timing is just right.

That concludes my remarks, Mr. Chairman, thank you.

[The prepared statement of Ms. Lombardo follows:]

PREPARED STATEMENT OF NANCY E. LOMBARDO, MEMBER, BOARD OF DIRECTORS
DETROIT CHAPTER, ALZHEIMER'S ASSOCIATION; AND VICE CHAIRMAN, NATIONAL
BOARD OF DIRECTORS, ALZHEIMER'S ASSOCIATION

Mr. Chairman and members of the Committee-

My name is Nancy Lombardo and I am a member of the Board of Directors for the Detroit area chapter of the Alzheimer's Association, as well as an alternate on the Association's statewide council. I am also a member of the Association's national board and the chair of its public policy committee.

Like so many others, Mr. Chairman, my involvement stems from personal experience. My mother has suffered with Alzheimer's Disease for 23 years. But as is so often the case, the devastation wrought by Alzheimer's Disease goes beyond the patient and touches the lives of families and loved ones as well. Our case is no exception. The prolonged course of this disease not only attacked a loving, productive, and otherwise healthy person, but also placed enormous physical, emotional, and financial strain on her family. My mother has been a Medicaid patient for over 10 years. Measured in dollar terms, the cost of caring for her at home for 8 years and in a nursing home for 14 years exceeds \$400,000.

By way of background, the Alzheimer's Association is a national voluntary health organization comprised of family members, caregivers, scientists, health professionals, and concerned citizens. With support from private contributors, the Association has mounted a nationwide effort to conquer a disease that robs its victims of their ability to function as productive members of society and, ultimately, their dignity.

Working through 200 chapters, 1,500 family support groups, and 30,000 volunteers, our Association is committed to finding the cure for this dread disease, as well as easing the burden of the more than 4 million victims, their families and loved ones.

Before I present our Association's recommendations, I would like to take this opportunity to publicly thank you Mr. Chairman for your leadership and longstanding support for this effort.

You were our shining light of hope at a time when few were willing to tackle this very difficult and devastating problem. This Committee held one of the first hearings on the subject of Alzheimer's Disease. And thanks to your efforts, the Appropriations Committee has consistently voted to increase support for medical research.

As this Committee is well aware, the 20th century has witnessed one of the most dramatic demographic shifts in history. In 1900, 1 in 25 Americans was over the age of 65; by 1986, 1 in 8 was at least 65. Looking at it another way, breakthroughs in medical science and better living standards have extended our lifespan. In 1940, only 7.4 percent of those who reached age 65 could be expected to live to age 90; by 1980 that had risen to 25.4 percent.

This growth in the elderly population is obviously having a tremendous impact on health care in this country. The largest portion of health care spending in the U.S.-- an estimated \$167 billion in 1987-- is spent on people over age 65. Of course, as the baby boom generation shoulders its way into the 21st century we can expect an even greater strain on this country's health care resources.

It is a sad irony that as our National leaders struggle to find ways to control rising health care costs, few consider the most obvious alternative. For while the elderly consume a disproportionately large share of health spending, they receive comparatively little attention when it comes to research.

No where is this disparity more evident than in the case of Alzheimer's Disease.

Taking into account the cost of providing care, lost wages, and lost productivity on the part of family caregivers, the National Institute on Aging has estimated that Alzheimer's Disease costs society over \$80 billion annually. Yet the federal government is only devoting the equivalent of one-tenth of one percent of that amount to finding a cure or treatment. Looking at it another way, current research expenditures for Alzheimer's Disease amounts to about \$30 per patient-- as compared to an average \$22,000 spent last year to care for an Alzheimer patient.

A National Commitment is Required

With support from the Association and federal research dollars, scientists have begun to unravel some of the mysteries surrounding Alzheimer's Disease. For example, researchers now suspect that certain nerve cells are vulnerable to neurological diseases associated with aging, such as Alzheimer's. Some believe that treatment with a human nerve growth factor might prevent degeneration of brain cells and perhaps improve memory impairments. Also, the discovery that a gene may be the key to an inherited form of the disease could lead the way to new insight into what causes Alzheimer's.

In order to pursue these and other promising leads, the pace of research must be accelerated and the federal investment greatly expanded.

That is why the Alzheimer's Association is urging Congress and the President to establish a national commitment, similar to the war on cancer that was launched in the early 70s. The centerpiece of that commitment would be a research goal of \$500 million by 1992. As down-payment, we are urging Congress to appropriate at least \$225 million for Alzheimer's research in FY1990.

Meeting the Care Needs of Alzheimer Patients and Families

We must never lose hope that one day scientists will find the answer. Nor can we ignore the present day needs of patients and their families.

Seventy percent of the victims of Alzheimer's Disease are being cared for at home by their families and friends-- usually without any help or financial assistance from outside sources. The services they need-- respite care, in-home health care, and adult day care-- are not accessible, too expensive, or simply nonexistent or closed to Alzheimer patients.

Of course, many of these families must eventually turn to nursing homes to provide care and supervision in the final years of the disease. But once again, they find no helping hand. The only option they have is to deplete their resources, become impoverished then turn to Medicaid.

Last year, our Association was proud to support home care legislation you sponsored along with Senator Pepper. Naturally, we shared your disappointment when the legislation was defeated on a procedural motion. But as you well know, that defeat does not change the fact that families throughout the country are still facing a daily struggle to care for their chronically ill loved ones.

On behalf of the families and concerned citizens who make up our Association, and as members of the Long Term Care Campaign, we are urging members of Congress to address this most pressing need and provide comprehensive long-term care social insurance protection to Americans of all ages and incomes.

As you and your colleagues in Congress begin to address the need for long-term care, I hope you will keep in mind some of the special needs relating to Alzheimer patients. Chief among them is the criteria used for determining eligibility. It is important to recognize that traditional measures, such as the inability to perform certain activities of daily living, simply do not accurately assess the needs of all individuals with cognitive impairments.

Second, the benefit package provided should take into account the special needs of families caring for dementia patients by covering the full range of required home, community-based, and nursing home services.

And most importantly, we strongly urge that the cost of providing long-term care coverage be spread as broadly as possible to avoid placing undue financial hardships on individuals or families in need.

For the record, I would like to submit a more extensive listing of the basic principles that our Association would like to see incorporated in a long-term care program.

Developing a Family Support Partnership

Finally, Mr. Chairman, I would like to address the support and service needs of the forgotten victims-- the families and friends who care for Alzheimer patients.

The Alzheimer's Association is and always will be a family-based organization. Its roots consist of a network of nearly 200 chapters and 1,500 family support groups spread throughout the country. And what goes on at that level is truly remarkable.

The average chapter maintains phone lines on a 24-hour basis. Thus, individuals calling in for help can be linked with volunteers who can provide counseling, information, referrals, and sympathetic understanding from someone who has been through experiences similar to those of the caller.

Meetings are held weekly or monthly and are open to all. Most of the meetings provide speakers on subjects of interest from the field of medicine, law, social services, and finance. Usually time is set aside for sharing concerns and advice, as well as suggestions for coping. Also, some chapters are able to sponsor day care centers, respite care, and boarding care.

I mention this, Mr. Chairman, to underscore the fact that Alzheimer's Disease is a national problem and therefore requires a concerted effort at all levels.

To reach those families who are in desperate need requires a collaborative effort-- one that includes federal and State governments as well as the private and voluntary sectors. The role of the federal government, in this instance, should be to provide the overall policy guidance and resources necessary to stimulate State action. States, in turn, should capitalize on the front line experience and know-how found in our chapters.

To date, more than 30 States have implemented Alzheimer programs of one type or another. The legislation you are proposing would not only strengthen those existing programs but also help forge that kind of partnership throughout the remainder of the country.

Conclusion

Mr. Chairman, on behalf of our Association I want to thank you once again for advancing the critical issues facing our families. The legislation you are introducing today will go a long way towards helping address those issues and I want you to know that you have our full endorsement. We will do all we can to support quick enactment of the bill.

Thank you.

The CHAIRMAN. Thank you, Ms. Lombardo. The Chair now recognizes Mr. Moll.

STATEMENT OF RICHARD MOLL, ACTOR IN TELEVISION'S "NIGHT COURT" SERIES WHOSE FATHER WAS STRICKEN WITH ALZHEIMER'S DISEASE; REPRESENTING THE LOS ANGELES CHAPTER OF THE ALZHEIMER'S ASSOCIATION

Mr. MOLL. Thank you, Mr. Chairman. It is an honor to be here today.

Before I begin, I would like to thank my wife, Laura Moll, for her assistance in preparing this statement. Thank you.

As my father was growing older, I remember hearing him say, time and again, "I just can't remember things as well as I used to," but I didn't take it too seriously. My father was something of a worrier.

Then one day on a trip to the county fairgrounds to see the races, he told my mother that he was going to the rest room. He didn't return. My mother asked an attendant to check the rest room. He wasn't there. After a long and rather frantic search, she found him, standing by a fence, looking lost and bewildered.

Several months later, my father dropped my mother off for an appointment. Recalling his disorientation at the fairgrounds, my mother gave him the keys to the house and a note about her location and phone number. My father drove home. When he got there, he found that somehow he couldn't unlock the door. He got back in his car and started driving around town aimlessly. Eventually he wound up, for some strange reason, at an optometrist's office. They noticed his confusion, somehow discovered the note, and called my mother. My father was unable to go get my mother. She had to come for him.

The time would soon come, after many loud protests, that my father would have to give up driving altogether. It was the first of many things that he would have to give up.

Then came the day in the doctor's office when my mother heard the news: my father had Alzheimer's. And then the real shock: Alzheimer's is irreversible. Our only prospect was further deterioration. I remember thinking, "How do we know this is Alzheimer's? We used to call this sort of thing senility. Maybe he's just getting old." Perhaps I just didn't want to accept it. But to this day, I cannot swear to you that he died from Alzheimer's. I think there is a lot of ignorance about the disease.

My parents had a habit of going to lunch at the Senior Citizen's Center in Placerville, California, where they lived. But soon my father, who could sometimes be irritable under normal circumstances, became so aggressive that he had to be isolated from the other seniors. There was no adult day care center in their town, a place where people in his condition should join others in activities under the supervision of trained personnel. Eventually my father's behavior forced my parents to stop going to the Senior Center altogether. My mother was cut off from her only social outlet. She became a virtual prisoner in her own home.

During my infrequent visits to my parents' house, I would hear my father mutter something like, "Humpty Dumpty." I don't

know if I'm quoting him right on the money here but I hope it's close. That is one of the symptoms of the disease. The sufferer sometimes harkens back to the phrases of childhood. It's a very frustrating disease. I tended to miss my father even when he was sitting right in front of me. I just wanted to say, "C'mon, Daddy, let's go fishing!" like the old days. It would have been great just to have a conversation with the old Harry Moll.

I also remember feeling hopeful when I read about this doctor, who shall remain nameless, who had come up with a new treatment for Alzheimer's patients—a drug, I believe. I tried to get through to this doctor to get treatment for my father. All I could get on the phone were secretaries. I tried going through the ADRDA, Alzheimer's Disease and Related Disorders Association, my friends there, and they couldn't get through to him either. I told the secretaries that I was on Night Court, a hit television series. It cut no ice. I was told to fill out an application and send it in. When I received the application, I noticed that for the privilege of working in a research project with this doctor, one was required to send money up front, even before being accepted. Sometime later, I read in the newspaper that this doctor and his program had been discredited. For my money, it was a scam.

Let me be honest. I was hundreds of miles away, but I could have done a lot more than I did. Let's face it, when you know there is someone else there to do the unpleasant chores, it's mighty easy to sit back and let them do it. It is human nature. And so the elderly spouse is left holding the bag.

I've been asked to come here today to speak about Alzheimer's disease and about my father, who suffered from it. But in the last analysis, maybe I'm not the one who should be doing the talking, because I'm not the one who had to take care of him. I didn't have to bathe him. I didn't have to dress him in the morning and undress him at night. I didn't have to feed him three times a day. I didn't have to take him out walking while he moved along with the slow, small steps of the very aged. I didn't have to administer to his every need and whim and suffer the brunt of emotional outbursts springing from, or made worse by, the disease. I wasn't the one who was awakened on the average of three times a night if he needed a glass of water, or to go to the bathroom. And I wasn't the one that was forced to stay home day after day, getting only one 5-hour period off each week when I could get out of the house to go shopping, be with other people or just be alone, because there was no one else to care for him.

This unenviable job fell to my mother, Violet Anita Moll, who will be 82 years of age in April. She was married to my father, Harry Findley Moll, for 51 years. Violet took care of Harry for about the last 5 years of his life. Eventually, she was able to hire a practical nurse for \$6 an hour from an organization called the Eskaton Health Corporation, so she could leave the house once a week for that 5-hour stretch.

But the time finally came when my father lost control of his bodily functions and the family thought it best to put him in a local nursing home, which didn't take Medicare, by the way; I would mention that. I think we delayed it that long because we just figured he would put up too much of a ruckus if we tried to do

it earlier. It seemed like it would just be too difficult. Actually, it wasn't that hard once we finally did it.

What about those nursing homes? My mother says that whenever she would visit, it would always seem that the older, experienced staff were busy writing down things in the office, while the younger, less qualified and perhaps more callous personnel, were out handling the patients. I suppose it's a tough job. I suppose it's easy to get frustrated and stop thinking of the patients as human beings and start thinking of them as things. My mother heard stories of attendants serving dinner to the patients but not bothering to cut the meat into bite-sized pieces so they could eat it. She heard of attendants just standing old people under the showers, no scrubbing, no bathing, just stand them there under the showers and turn the water on full blast.

All I know is that my mother cared for my father for 4 years and 9 months. Once he was in the nursing home, he lasted 2 months, and 1 month in the hospital. Then in September of 1987, at the age of 85, he was gone.

Now you've heard our story. And the truth is, apart from occasional helpful visits from my two sisters, Julie Donelson and Mary Baldwin, and some financial aid from me, my mother had to do it all herself.

My question for you is: Why did she have to? Was it because of: Number 1: Public and professional ignorance of Alzheimer's and related diseases; Number 2: A real lack of services available for families caring for Alzheimer's patients in the home—and Mr. Chairman, Number 3: A serious shortage of nursing homes specializing in the care of Alzheimer's patients.

I think it is time for us to be aware of these things. Because with Alzheimer's, we are still in the Dark Ages. Thank you.

THE CHAIRMAN. Thank you, Mr. Moll. The Chair now recognizes Mr. DeLay.

STATEMENT OF FRANK DE LAY, MEMBER, AMERICAN ASSOCIATION OF RETIRED PERSONS BOARD OF DIRECTORS

Mr. DeLay. Thank you, Chairman Roybal. My name is Frank DeLay and I am a member of the Board of Directors of the American Association of Retired Persons. On behalf of our membership, I want to commend you for holding these hearings. The AARP believes that Alzheimer's disease and its affect on the development of a long-term care system deserve close attention. We must gain a greater understanding of the disease if we are to meet the needs of its victims, their families and caregivers, most of whom are spouses and daughters.

Alzheimer's disease and related conditions are chronic, progressive diseases that attack the brain. They cause loss of memory, personality, functional ability and ultimately, they cause death. It is the fourth leading cause of death among persons 65 and older. In many ways, Alzheimer's itself is like death, the death of a mind. To be a member of an Alzheimer's family is to taste the bitter stool of frustration, anger, guilt, embarrassment and grief.

We know relatively little about the long-term care needs of this group because most research has focused on physically impaired

people. We need a better understanding of the methods for assessing cogitative impairments and how they influence the need for formal and informal care. We need to refine assessment tools to measure the degree of impairment more precisely and we need to develop skills that measure functional impairments based on physical and cognitive assessment and skills adapted to different age groups. Without question, the National Institute on Aging needs to increase funding levels for Alzheimer's disease research. As you said, Mr. Chairman, we are spending only about one \$1 on research for \$500 of care. This discrepancy cannot continue.

Victims of Alzheimer's disease can receive care at home if a spouse or their caregiver is available. However, the disease is chronic and can last from 5 to 20 years. Such a long period of illness places greater emotional, physical and financial burdens on family and friends. The caregivers of Alzheimer's victims are predominantly adult children and spouses. Seventy-five percent of them are women who are both the primary recipients and providers of long-term care. Many of the spouses are themselves elderly, poor and in ill health.

Families can easily spend \$12,000 a year for care of a dependent adult at home. They can subsequently spend \$25,000 a year for several years of nursing home care when the individual can no longer function at home. These financial costs can easily impoverish a family. Medicaid will pay for nursing home care and in some States, a limited amount of home care. However, the program is inadequate because it does not cover home care except for restrictive waivers, coverage varies greatly from State to State, and the process of becoming eligible, since it is a means tested welfare program, often robs families of dignity and independence.

The plight of Alzheimer's disease victims and their families demonstrates the need for a new approach to long-term care in this country. AARP recommends a social insurance approach that protects all Americans from impoverishment and lack of care.

Social insurance would require financial contributions from all members of society and would provide protection to all who need long-term care, regardless of age. The services offered should be inclusive, including nursing home care, day care and in-home care.

Identifying realistic and adequate funding sources for a comprehensive long-term care program is difficult but four opinion polls have found that approximately 60 percent of American voters are willing to pay increased taxes to fund the program. Our attention is focused on payroll, estate and gift taxes, affordable beneficiary copayments, deductibles and premiums and maintenance of government spending on current long-term care programs, such as Medicaid.

In evaluating various possibilities, we are guided by several general assumptions. First: The burden of paying for long-term care should be shared between the retired and working-age populations. Second: Any new Federal commitment to long-term care should not add to the Federal deficit. Third: Mechanisms must be established to keep cost and the use of services Under control. Finally, the system must not create perverse incentives for delivery of care in a particular setting. Although long-term care insurance is the most promising of the private sector options, there are major barriers to

its development. These include the high cost of policies, limitations and restrictions in coverage and lack of inflation protection. Most plans also require prior institutionalization as a condition of benefit coverage and provide inadequate home care benefits.

Due to the private sectors limitations, we believe that the primary answer to long-term care financing dilemma lies with the public sector, but AARP also encourages the development of private sector approaches which can compliment our search for solutions for financing long-term care. Under a social insurance system, private sector approaches should supplement the public system by covering copayments, deductibles and extra services. All private sector approaches should also include strong consumer protection standards.

In conclusion, it is critical to recognize that the costs of long-term care are not now borne by society but are borne by the victims of illness and their families. A publicly provided program would help to spread these costs in a more affordable manner across the population, while assuring all our citizens access to care. In constructing such a program, we must ensure that the needs of the people with cognitive impairments are measured accurately and that the program meets these needs. Thank you, sir.

[The prepared statement of Mr. DeLay follows:]



STATEMENT OF THE
AMERICAN ASSOCIATION OF RETIRED PERSONS
before the
HOUSE SELECT COMMITTEE ON AGING
on
CARING FOR ALZHEIMER'S VICTIMS

Presented by:

Frank DeLay

Member, AARP Board of Directors

March 21, 1989

American Association of Retired Persons 1909 K Street, N.W., Washington, D.C. 20049 (202) 872-4700

Louise D. Crooks *President*

Horace B. Deets *Executive Director*

Thank you, Chairman Roybal. My name is Frank DeLay and I am a member of the Board of Directors of the American Association of Retired Persons. On behalf of our membership, I want to commend you for holding these hearings. AARP believes that Alzheimer's disease and its affect on the development of a long-term care system deserve close attention. We must gain a greater understanding of the disease if we are to meet the needs of its victims and their caregivers.

My testimony will show why the plight of Alzheimer's disease victims and their families demonstrates the need for a new long-term care system based on the principle of social insurance. My testimony also discusses the need for additional research into the causes and measurement of Alzheimer's disease and related disorders. Finally, the broad outlines of the type of long-term care system AARP favors will be addressed.

OVERVIEW OF ALZHEIMER'S DISEASE

Alzheimer's disease and related conditions are chronic, progressive diseases that attack the brain. They cause loss of memory, personality, functional ability, and ultimately, they cause death. More than 2.5 million Americans suffer from these diseases. Most victims are age 65 and older, although some people under age 65 are afflicted. It is the fourth leading cause of death among people age 65 and older.

The primary characteristic of Alzheimer's disease is memory loss. In the early stages, people are often anxious, forgetful, or disoriented. As the disease progresses, their memory grows worse and they may forget their spouses, their addresses, or how to perform typical activities of daily living. Loss of mental functioning is usually accompanied by loss of physical functioning. Many victims of this disease cannot prepare their own meals, manage their money, or maintain their households. In time, they lose their ability to perform even more basic tasks such as walking, bathing, dressing, or eating.

Some people may not lose physical functioning but may require continuous supervision. Memory loss or other mental deterioration can result in behavior problems that cause individuals to endanger their own safety or the safety of others. For example, an individual may be able to prepare his or her own meals but may forget to turn off the gas on the stove.

Victims of Alzheimer's disease can receive care at home if a spouse or other caregiver is available. However, the disease is chronic and can last from 5 to 20 years. Such a long period of illness places great emotional, physical, and financial burdens on family and friends.

The caregivers of Alzheimer's victims are predominantly adult children and spouses. Seventy-five percent of them are women. Many of the spouses are themselves elderly, poor, and in ill health. Many of the adult daughters, typically middle-aged women, who are caring for parents are working outside of the home -- caught between trying to help with a child's college education and trying to give a frail parent the help she needs.

More than a decade of research has documented that caring for the dependent elderly is difficult emotionally, physically, and financially. Families can easily spend \$12,000 a year for care at home. They can subsequently spend \$25,000 a year for several years of nursing home care when the individual can no longer function at home. These financial costs can impoverish a family. Medicaid will pay for nursing home care and, in some states, a limited amount of home care. However, the program will only pickup these costs after the victim has depleted his or her financial resources. The plight of the Alzheimer's disease victim and his or her family demonstrates the need for a new approach to long-term care in this country.

INSUFFICIENT DATA ON COGNITIVE IMPAIRMENTS

Any new long-term care system must meet the needs of people who have cognitive impairments. Such impairments have a great impact on an individual's ability to function independently. Most cognitively impaired people live with another person because of their increased needs for assistance or supervision.

People with Alzheimer's disease are only one part of a larger group of older people with cognitive impairments. The number of people with such impairments generally is unknown. Additionally, we know relatively little about the long-term care needs of this group because most long-term care research has focused on physically impaired people. We need a better understanding of the relationship between physical and cognitive impairment and improved methods of assessing cognitive impairments. We also need to understand how different types of physical or cognitive impairments influence the need for formal and informal care.

MEASUREMENT OF IMPAIRMENTS

Functional status has multiple dimensions: physical functioning, cognitive functioning, social functioning, and emotional functioning. Several tests have been developed to measure physical functioning. They include the activities of daily living scale, the Social Security Disability scale, and the instrumental activities scale. However, measures of cognitive impairment are not well developed.

The activities of daily living scale identifies people with limitations in as many as seven activities: walking, bathing, getting outside, transferring from a bed or chair, dressing, using the toilet, and eating. Research literature contains many studies of this scale, which is used in assessing the functional limitations of the older population.

The Social Security Disability scale identifies difficulties in performing activities that are related to a person's ability to work. The instrumental activities of daily living scale identifies problems in home management such as inability to prepare meals or to manage money.

Psychologists often measure emotional functioning using depression scales. However, there has not been sufficient experience with many scales to generate norms for emotional functioning. Although many scales have been developed, no clear criteria for use with older people in this area has yet emerged in the research literature.

Cognitive impairment is harder to measure and is less well defined than physical impairment. There are two general approaches: structured tests and clinical observation. A structured assessment could include performance tests or psychological tests. Performance tests are used more frequently than self-reported information, and most tests determine a person's orientation to time and place. Researchers have found that people who do not perform well on these tests are likely to have diagnosis of dementia or other mental disorders that result in cognitive problems.

Clinical observation includes an evaluation by a physician or other health care professional. The evaluation determines memory loss, communication problems, disorientation, and other cognitive or behavioral changes. The evaluation may also include an assessment of problems experienced by the patient's caregiver.

These two approaches do not necessarily lead to a diagnosis. Both structured tests and clinical observation provide only a rough estimate of cognitive impairment. After all, an older person may not respond well to a test because of depression or other problems. A physician can make a definite diagnosis only after repeated assessments; ultimately the diagnosis can be verified only with postmortem examination.

ADDITIONAL RESEARCH

Clearly, the National Institute on Aging needs to increase funding levels for Alzheimer's Disease research so that we can better understand the many facets of this widespread problem. Currently, we are spending only about one dollar on researching the causes and cures for this disease for every \$250 we spend on

institutional care for its victims. This discrepancy cannot continue.

In the future, we need to refine assessment tools to measure the degree of impairment more precisely. We also need to develop scales that measure functional impairments based on physical and cognitive assessment and scales adapted to different age groups. Different scales are necessary because certain measures, such as limitations in activities of daily living, are not useful for assessing impairment in chronically ill children who may not be able to perform an activity because it is not appropriate to their age, rather than because of a physical or cognitive impairment. In addition, a person with Alzheimer's disease may perform a physical activity at one time but, later, may not be able to perform it, or may not remember how to perform it without supervision.

In addition to information provided by more precise measurement tools, policy makers need answers to several other questions. For example, what long-term care services are most appropriate for people afflicted with Alzheimer's disease and related conditions? How much will these services cost? What is the role and cost of community services? What are appropriate national standards of care for treating Alzheimer's victims? What kind of special training for caregivers is needed? How can we prevent nursing homes from discriminating against Alzheimer's victims? How can we encourage nursing homes to develop special care units for victims?

AARP'S RECOMMENDATIONS FOR A NEW LONG-TERM CARE SYSTEM

AARP recommends a social insurance approach that protects all Americans from impoverishment and lack of care. Social insurance would require financial contributions from all members of society and would provide protection to all who need long-term care. The remainder of my testimony discusses the Association's recommendations for a long-term care program based on social insurance.

Our country's primary governmental long-term care program, Medicaid, is inadequate for several reasons: 1) the Medicaid program does not cover home care except through special waivers; 2) among the services which Medicaid can provide, the degree of coverage varies dramatically from state to state; and 3) because it is a welfare program, Medicaid often robs families of dignity and independence. Beyond Medicaid, our society is paying the costs of long-term care but in a way that places burdens on the victims of chronic illness and their families. The question before us is how to spread the burden so that the costs to any one person will be small, while offering protection and appropriate care to all. The answer is a social insurance, rather than a welfare, approach.

The nature of the need for long-term care lends itself to an insurance approach based on shared risk for several reasons: 1) relatively few persons in our society need long-term care at any one time; 2) it is nearly impossible to predict who these individuals will be; and 3) the lifetime risk of needing nursing home care is much higher than most people think. (The lifetime risk of institutionalization at age 65 ranges from 36% to 63%.) This combination of factors shows the need for and the utility of an insurance approach to universal protection. The costs to any one person will be small, while offering protection to all against financial devastation.

Americans of all ages recognize that long-term care is a growing necessity. While many underestimate the costs and the likelihood of their needing such service, surveys have demonstrated that the public is willing to participate in and pay for a social insurance approach.

AARP's proposals for long-term health care encompass a number of issues and concerns. All Americans, regardless of age should be eligible for long-term care programs. The services offered by a nationwide long-term care program should be inclusive. Nursing home care, day care, and in-home care all constitute particular and valuable resources to severely-disabled Americans who require assistance.

Some state governments already have experience in administering long-term care programs, and the Federal government would be well-served by a study of their experiences. These states have introduced a variety of programs and have demonstrated how flexibility and creativity in providing care can keep costs down while maintaining quality.

The federal government, however, must oversee development of long-term care programs to ensure that all Americans have access to quality services. Oversight must include strong standards relating to eligibility, services, administration, quality of care and provider reimbursement.

Eligibility for the New Program

Americans of all ages should have access to a new long-term care program. Chronically ill children and adults, as well as permanently disabled people, need access to long-term care. The lack of coverage of home and community services poses enormous burdens for these individuals and the families and friends who support them.

Eligibility for benefits should be based on functional impairment, whether the cause is cognitive, emotional, or

physical. Eligibility should not, however, be based on a diagnosis of a particular disease. Many people, particularly those who have Alzheimer's disease, may be physically capable of performing activities of daily living but unable to do so because of cognitive impairments, therefore they are functionally impaired. In determining eligibility for the program, in-person assessments and interviews with caregivers will be critical to gathering accurate information about individuals' functional status, informal social supports, and requirements for service arrangements.

As discussed earlier, the issues surrounding measurement of impairments are complex. There are several different scales for measuring the need for help with activities of daily living and it is not clear how to measure the need for help among different age groups. Thus, we recommend that a commission be established to assist the Secretary of Health and Human Services in developing appropriate measurements of functional impairment, including a national, uniform assessment scale. The commission could provide advice on issues such as measurement of cognitive disabilities and the training needed by people who perform assessments.

Services under the New Program

AARP advocates that the program offer a wide range of long-term care services in the least restrictive setting possible. Services should include 1) in-home assistance, such as homemaker/chore services, personal care, home nursing care, and home-delivered meals; 2) community-based services, such as adult day care and transportation; 3) provision of home care services in special housing, such as congregate living arrangements; and 4) high quality institutional care. Another aspect of long-term care that merits consideration is respite care, which would provide short-term relief to unpaid caregivers, most of whom are family members. Such a broad range of services would ensure that Alzheimer's victims would receive care that is tailored to their needs and circumstances. This would ensure the most efficient use of resources.

Administration of the New Program

The Federal government should take a strong role in administering the long-term care program to ensure that consistent standards for eligibility, quality of care, and reimbursement are maintained nationwide. Service delivery systems and the profiles of populations needing long-term care vary widely between and within the states. Thus, states will need to have some flexibility to tailor programs to meet their residents' distinctive needs. In addition, states should have a role in administration because a number of states have set up good service delivery systems.

Given that some states have more developed long-term care delivery systems than others, there is a need to phase in the new program. During the phase-in period, states should have technical assistance and start-up grants to enable them to develop their systems. The grants should be used to identify and fill gaps in service delivery networks. Since long-term care is currently biased toward institutional care, the initial emphasis should be on home and community-based services.

While the federal government has a very strong oversight responsibility and the states have a role in administering the new long-term care program, case management agencies have the potential to make the program work at the local level. Case managers could have responsibility for determining program eligibility and beneficiaries' need for care; developing the appropriate plan of care; arranging for delivery of services; and helping to ensure quality of care. States with the most comprehensive long-term care programs have found that giving independent case management agencies responsibility for assessing peoples' care needs and for developing care plans promotes program efficiency. Thus, case management seems to hold promise both for helping people to secure appropriate services and controlling use of services. Appropriate use of services is the key to keeping utilization and program costs under control. More research is needed to determine the best case management models and the appropriate role of these agencies.

Provider Reimbursement

Provider reimbursement systems for long-term care services should be designed to ensure the delivery of quality care. Payment should also ensure that cost increases are controllable. Reimbursement should be accepted as payment in full so that providers do not try to overcharge residents or clients. States, through their nursing home reimbursement systems, have begun to deal with these issues, and their experiences should be examined for applicability to a federal system.

For example, a number of states have developed "casemix" reimbursement systems that are designed to encourage nursing homes to accept heavy-care patients and deliver the appropriate amounts of care. New York's resource utilization group system (RUGS) pays nursing homes according to the amount of resources necessary to care for residents. The heavier the residents' care needs, the higher the level of reimbursement. Such reimbursement systems can improve access to nursing home care for the most vulnerable residents. Other states, such as Oregon, are beginning to develop nursing home reimbursement systems that would relate payment levels to resident outcomes. The idea is to go beyond casemix reimbursement and reward nursing homes that, in accordance with the plan of care, deliver care that improves or

maintains residents' functioning. Providers would not be penalized when residents' functioning declines as a result of a debilitating disease.

To contain cost increases under Medicaid, almost all states use some form of prospective payment for nursing homes. This type of reimbursement system encourages facilities to contain costs because they are not reimbursed for charges that exceed the payment rate. For example, if a facility spends more than the prospective rate allows on administrative overhead, it will not be paid for the excess charges. Under any program, it is essential to use a payment system that keeps cost increases at reasonable levels. However, payment rates should not be so low as to undermine delivery of quality care.

With regard to payment for home care, there is less of a track record at the state level. Thus, there is a need for research to determine the best methods of paying for home care. The research should focus on prospective payment that accounts for casemix and outcomes. Such a payment system should also be flexible in order to account for the varying needs of home care clients. For instance, some people may need short periods of intensive skilled nursing care, and others may need long-term help with activities of daily living.

Quality Assurance

Under a new long-term care program, the federal and state governments would be taking a much more direct role in the financing of care. There should be a concomitant increase in the Federal government's responsibility for ensuring the quality of care that providers deliver. To ensure nursing home and home care quality, the new program should build upon the landmark Nursing Home Reform legislation the Congress passed in 1987 as part of the Omnibus Budget Reconciliation Act.

Additional quality standards for provider participation in the long-term care program should address the following goals: 1) plans of care and actual services delivered must meet client and caregivers' needs; 2) providers should not be allowed to discriminate in admissions or service delivery on the basis of payment source; and 3) social isolation of clients should be prevented. In addition, case managers should be involved in the quality assurance process by eliciting clients' views of the quality of care.

State ombudsperson programs also should be expanded to have responsibility for investigating and resolving complaints about all types of long-term care providers. Local consumer councils should be involved in such quality assurance efforts.

Financing the New Long-Term Care Program

Identifying realistic and adequate funding sources for a comprehensive long-term care program is one of the toughest issues which the Congress and advocates of long-term care must address. AARP advocates a social insurance approach to funding. Our attention is focused on payroll, estate and gift taxes; affordable beneficiary copayments, deductibles, and premiums; and maintenance of government spending on current long-term care programs such as Medicaid. In evaluating various possibilities, we are guided by several general assumptions.

1. The burden of paying for long-term care should be shared between the retired and working-age populations.
2. Any new federal commitment to long-term care should not add to the federal deficit.
3. Mechanisms must be established to keep cost and use of services under control.
4. The system must not create perverse incentives for delivery of care in a particular setting. For instance, copayments for home care should not be excessive compared to those for nursing home care.

The Role of the Private Sector

Private sector options for financing long-term care include private long-term care insurance, home equity conversion plans, and the prospect of long-term care individual medical accounts. Although long-term care insurance is the most promising of these options, there are major barriers to its development. Barriers include: the cost of the policies (which typically range from about \$20 a month at age 55 to about \$120 a month at age 75); limitations and restrictions in coverage; and lack of knowledge about the need for protection against long-term care expenses. Benefits generally are not indexed for inflation, and may not keep up with escalating costs of care. Most plans require prior institutionalization as a condition of benefit coverage and provide inadequate home care benefits.

Although the private long-term care insurance market shows signs of growth, it is still in its infancy. While the number of policies in force (estimated between 500,000 and 1,000,000) is growing, they cover few of the 51 million Americans aged 55 and over. Recent projections by the Brookings Institution indicate that the proportion of total nursing homes care financed through private insurance by the years 2016-2020 will be between 7 and 12 percent at most, given favorable assumptions.

In addition, people in need often cannot purchase private

long-term care insurance. Few companies will sell insurance to people age 80 or over, or to people with pre-existing (potentially disabling) medical conditions. This practice may be necessary to maintain the financial stability of the insurance plan, but it leaves those most likely to need long-term care without any protection.

Due to the private sector's limitations, the Association believes that the primary answer to the long-term care financing dilemma lies with the public sector, but AARP also encourages the development of private sector approaches, at least as partial solutions, to the problem of financing long-term care. Such approaches present options to many people, and could provide valuable experience with management of services. Among the private sector approaches that should be considered are private long-term care insurance, home equity conversion plans, social health maintenance organizations, and continuing care retirement communities. Under a social insurance system, private sector approaches should supplement the public system by covering copayments, deductibles, and extra services. All private sector approaches should include strong consumer protection standards.

CONCLUSION

It is critical to recognize that the costs of long-term care are now borne by society but borne by the victims of illnesses such as Alzheimer's disease. A publicly provided program would help to spread those costs in a more affordable manner across the population, while assuring all our citizens access to care. In constructing such a program we must ensure that the needs of people with cognitive impairments are measured accurately and that the program meets these needs.

The CHAIRMAN. Thank you, Mr. DeLay. The chair recognizes Dr. Franklin Williams.

STATEMENT OF DR. T. FRANKLIN WILLIAMS, DIRECTOR, NATIONAL INSTITUTE ON AGING, NATIONAL INSTITUTES OF HEALTH, PUBLIC HEALTH SERVICE, DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, D.C.

Dr. WILLIAMS. Thank you, Mr. Chairman, and members of the committee. I am Dr. T. Franklin Williams, Director of the National Institute on Aging. I appreciate this opportunity to speak on a topic that affects the health, social well-being and economic security of millions of older Americans and their families. Virtually every person has a close relative or close friend with Alzheimer's disease.

I am speaking today on behalf of the Public Health Service to discuss the current status of research with respect to Alzheimer's disease and related disorders. I am glad to be joined by Dr. Gene Cohen, Deputy Director of our institute and also Executive Secretary of both the Council on Alzheimer's Disease and the Advisory Panel on Alzheimer's Disease, and Dr. Zaven Khachaturian, head of our office and program in Alzheimer's disease research, as well as Sandra Lindsay, our legislative representative.

Among the many disorders associated with growing older, Alzheimer's disease is one of the most devastating and most feared. With the rapidly increasing number of people living into their 80's and 90's, among whom at least one in five faces the likelihood of developing this disease, the burden of care and cost will become even more catastrophic than it is today unless we conquer this disease through research. Research holds the answer to what we seek.

As Ms. Lombardo has already testified, Alzheimer's disease probably afflicts 3 to 4 million people 65 years of age or older. The cost of care associated with this disease, as you stated, Mr. Chairman, is estimated at close to \$88-billion a year and will probably double by the year 2000 unless we achieve major scientific break-throughs.

Alzheimer's disease has been one of the highest priorities for the Department of Health and Human Services since the early 1980s. Research in this disease is supported and conducted by several institutes in the National Institutes of Health, and also by components of the Alcohol, Drug Abuse and Mental Health Administration.

At the departmental level, Alzheimer's disease research initiatives are coordinated through the DHHS Council on Alzheimer's Disease. A second group, the Advisory Panel on Alzheimer's Disease, consists of nonfederal experts on this disease appointed by the Director of the Office of Technology Assessment. This congressionally-mandated panel has been looking not only at the direction of research, but also at the scope of the studies and various policy considerations. Its first report will be submitted to Congress before the end of this month.

Since Alzheimer's disease is an area of interest to several institutes at the National Institute of Health, Dr. James Wyngaarden, Director, NIH, has created the NIH Alzheimer's Disease Coordinat-

ing Committee, located in our institute, to coordinate NIH-wide activities, as well as with other Federal agencies.

Within our institute, the search for the causes of Alzheimer's disease, better diagnosis, effective treatments and improved care for its victims is our highest priority, accounting for approximately one third of our total budget.

I would like to highlight a few of the very promising recent research advances. Others are given in my printed testimony. We have learned that even though there is a genetic predisposition to Alzheimer's disease in at least some persons, there must be other factors contributing to the onset of this disease. This is shown most clearly in instances in which Alzheimer's disease has occurred in one of two identical twins but not in the other. These twins have the same genes; therefore, some other factors in their lifestyle or environment must have contributed to bringing on the disease in the affected twin.

We have clues and are working to learn more about what such factors might be. These include: possible toxic substances in the food chain, similar to the cause of Parkinson's disease with dementia in an epidemic in Guam in previous years; possible environmental exposure, such as pesticides; and possible infectious agents, such as a recent provocative study which suggests that there may be a transmissible agent in this disease similar to other known slow virus infections. There is also evidence that this disease may be a systemic metabolic disorder, and thus might be modified or corrected through modifying this metabolic disturbance.

One of the most promising directions of research focuses on the role of nerve growth factors in restoring the function of damaged nerves. These growth factors have recently been shown to produce regrowth of nerve cells when administered to damaged areas of brains in experimental mice and rats and to improve these animals' abilities to perform maze tests, that is, improve cognitive function in the experimental animals. Our institute recently organized a special conference which has recommended plans for testing the value of nerve growth factors in persons afflicted with Alzheimer's.

A very recent related discovery, reported just this past week in the journal "Science" by two leading scientists, supported by the National Institute on Aging, indicates that the portion of the protein in brain cells which is a source of the amyloid deposits in the damaged areas of the brain in Alzheimer's disease, is actually normally a growth promoting factor. Thus, the deposits in the damaged areas may be an attempt at repair.

Other satisfying advances include the fact that, with the very careful clinical diagnostic workups developed in our Alzheimer's Disease Research Centers, the diagnosis of Alzheimer's disease can now be 100 percent accurate, as confirmed later by autopsy. This is a reassuring and very helpful step for many situations, including ones such as Mr. Moll referred to earlier in his own experience.

Other potential treatments for Alzheimer's disease are also in prospect. In addition to the careful clinical trial now underway on THA, or tetrahydroaminoacridine, which we expect to see completed this year, there are at least 5 to 10 other drugs which look sufficiently promising to warrant testing in the near future. Such drugs

may well produce at least temporary improvement in mental functioning and delay the downward course of the disease.

While we are moving as rapidly as we can on research on causes and possible means to prevent and treat this disease, we are also concerned with achieving the best support possible for the caregivers, who, as already noted, are primarily the family members and friends of Alzheimer's victims.

There are already a number of studies underway addressing caregiving issues. In addition, our institute, together with the new National Center for Nursing Research, the National Institute of Mental Health, and the National Center for Health Services Research, has just issued a program announcement calling for more research on the burdens of care, including particular emphasis on the needs of special populations, that is, the oldest old, racial and ethnic minorities, those with low income or little education, and those living in rural areas. What we can learn about better and more efficient care for Alzheimer's disease victims will also help us address long-term care needs for other frail, older persons.

Another important area is the dissemination of the latest information on Alzheimer's disease to the public, to family members, as well as to all types of professionals who contribute to the treatment of Alzheimer's disease patients. A number of major efforts have been and are being carried out to try to achieve these goals.

All of our 12 Alzheimer's Disease Research Centers have, by congressional directive, a dissemination role which they are carrying out in a number of different ways, utilizing approximately 10 percent of their funds. In addition, this past year the Administration on Aging added additional funds for the educational activities of these centers. The newly-established Alzheimer's Disease Education and Referral Center and Clearinghouse will work in conjunction with support groups to be a major source of current information for the public and caregivers and professionals.

In conclusion, Mr. Chairman, the Department's Alzheimer's Disease Council, the Advisory Panel on Alzheimer's Disease, and the NIH-wide Alzheimer's Disease Coordinating Committee have very effectively coordinated the efforts in this Department, together with the Veterans Administration and other agencies, in a collaborative focus on Alzheimer's disease.

Research to date has brought us considerably closer to unraveling the mystery surrounding the causes and cure of Alzheimer's disease, although the cause is not specifically known. Clinical studies have led to some progress in alleviating some of the excess disability of these patients, but there are still no treatments that can prevent, cure or halt the progression of this dread disorder.

Meanwhile, with the rapidly expanding number of older Americans, the prevalence of Alzheimer's disease continues to rise by alarming numbers. Research remains our best hope for ultimately reducing the terrible impact of this disorder on patient suffering, family burden and societal costs. Thank you, Mr. Chairman.

[The prepared statement of Dr. Williams follows:]

STATEMENT BY

T. FRANKLIN WILLIAMS, M.D.
DIRECTOR

NATIONAL INSTITUTE ON AGING
NATIONAL INSTITUTES OF HEALTH
PUBLIC HEALTH SERVICE
DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE

U.S. HOUSE SELECT COMMITTEE ON AGING

MARCH 20, 1989

Mr. Chairman, members of the Committee, I am T. Franklin Williams, M.D., the Director of the National Institute on Aging (NIA). Thank you for affording me the opportunity to speak on a topic that affects the health, social well-being, and economic security of millions of older Americans and their families. It is a pleasure to appear before you today on behalf of the Public Health Service to discuss the current status of research with respect to Alzheimer's disease and related disorders.

Introduction

Among the many disorders associated with growing older, Alzheimer's disease (AD) is one of the most devastating and most feared. With the rapidly increasing number of people living into their eighties and nineties, among whom at least one in five faces the likelihood of developing this disease, the burden of care and costs will become even more catastrophic than it is today, unless we conquer this disease through further research.

Alzheimer's disease is estimated to afflict from 2.5 to well over 3 million people 65 years of age or older in the United States. Moreover, as the population grows older, an ever-increasing proportion of older Americans will be at risk for this devastating disorder of the mind. While under 5% of those 65-74 years of age are affected, over 25% of those 85 and older suffer this disorder--and this fastest growing age group in the country. The projections for the near and distant future are indeed very bleak. By the year 2000, a short eleven years from now, it is estimated that nearly 5.0 million people will have the diagnosis of probable AD. The cost of care associated with this disease, estimated at \$80 billion a year for those now afflicted, will therefore almost double by that year.

The crucial question facing us today is: How can we deal with this health crisis of epidemic proportions? It is clear that the only answers to minimizing the enormous burden of care and costs will stem from further research, leading to ways to prevent, halt, or treat this disease.

AD has been one of the highest priorities for the Department of Health and Human Services (DHHS) since the early 1980s. Research on AD is supported and conducted by the National Institutes of Health (NIH), and by the Alcohol, Drug Abuse and Mental Health Administration. The Department has made a special effort to coordinate AD-related activities at several levels.

At the Departmental level, AD research initiatives are coordinated through the DHHS Council on Alzheimer's Disease. The members of the DHHS Council on AD, chaired by the Assistant Secretary for Health, represent the various programs in DHHS and the Veterans Administration that are significantly focused on AD. The Council works to share information about research progress on AD, and to identify promising new directions for investigation. It has published various reports in this regard.

A second group, the Office of Technology Assessment (OTA) Advisory Panel on Alzheimer's disease, consists of non-federal experts on AD appointed by the Director, OTA. This congressionally-mandated Panel has been looking not only at the directions of research, but at the scope of these studies as well, along with various policy considerations in this area. It will release its first report soon.

Since AD is an area of interest to several Institutes at NIH, Dr. James B. Wyngaarden, Director of NIH, created the NIH Alzheimer's Disease Coordinating Committee (ADOC), which is located at NIA, to coordinate NIH-

wide activities. This Committee has been active and meets at least monthly. Often the Committee involves other agencies such as the Food and Drug Administration (FDA) and the Administration on Aging (AoA). Within the Institute itself, the NIA Office of Alzheimer's Disease Research coordinates all AD-related activities.

I would like to take this opportunity to review with you the status of Alzheimer's disease research conducted and supported by the NIH and ADAMHA. A number of NIH institutes are involved in research related to AD, however four in particular have active programs in biomedical AD-related research: the NIA, the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Allergy and Infectious Diseases (NIAID), and the Division of Research Resources (DRR).

NATIONAL INSTITUTES OF HEALTH

The National Institute on Aging (NIA)

The search for the cause(s), better diagnosis, and effective treatments of AD is one of the highest priorities of NIA. Work related to AD is carried out in virtually all components of the Institute. Approximately 30% of NIA's budget is devoted to these efforts.

a. Causes of Alzheimer's Disease

The search for the cause(s) of AD focuses on the problem of why nerve cells in certain parts of the Alzheimer patient's brain are selectively vulnerable to death. Scientists now have some very exciting leads, and the prospects of solving this problem are good. Research into the possible reasons for selective cell death include studies on: decline in the supply of growth factors which maintain the functioning of cells in the brain; the

formation of abnormal proteins such as amyloid; genetic vulnerability; exposure to toxins derived from the environment and/or certain foods; changes in the ability of nerve cells to metabolize sugar; increased levels of stress-related hormones, and decreased blood supply to the brain.

Several studies supported by NIA have indicated that in old animals, as well as in surgically-treated experimental animals, nerve growth factor (NGF), as well as other growth-promoting agents, may normally act to support the viability and functioning of nerve cells. Treatment with NGF has been shown in experimental animals to prevent injury-induced degeneration of brain cells and can improve cognitive functioning in old animals with memory impairments. The potential use of NGF in treating AD has been proposed by many respected scientists. The NIA convened a scientific panel in August 1988 to develop a national strategy for clinical trials to test the efficacy of NGF treatment in AD. The recommendations of this meeting were published, and NIA is proceeding with the recommendations of this conference.

Genetics may also play a role in AD. In July of 1988, a group of investigators from Yale University reported that they had identified an infectious agent derived from the blood of Alzheimer's patients and some of their relatives in a family with genetic predisposition to this disease. The infectious material was used to transmit disease to hamsters. This preliminary study indicated that, after two successive transmissions, the agent retained its infectivity and produced neuropathological changes often seen in neurodegenerative diseases of man. The investigators speculate that in genetically predisposed persons a viral infection may precipitate the

slow development of AD, similar to certain other so-called slow virus diseases.

This study, however, was conducted with few patients and a small number of animals. Shortly after this study was reported, NIA called upon several investigators who have the necessary specialized skills and facilities to initiate a multi-center cooperative study designed to replicate and possibly confirm the Yale study.

There is also growing evidence that endogenous and exogenous toxins may be involved in causing AD. For example, one of the neurotransmitters (glutamate) normally produced by the brain can, in excessive amounts, serve as a toxin and kill nerve cells. A chemical constituent of the starchy fruit of the cycad plant, sometimes used in Guam and other Pacific settings as a food source, has been shown to produce brain damage including dementia. Recent findings also indicate that certain pesticides used in farming may also contain toxins that specifically attack the nervous system. This possibility led the NIA to convene a small working group of experts to design a study on the relationship between pesticide exposure and the incidence of increased neurological disorders in older farm workers and migrant farm workers. The NIA is ready to initiate a major study on this problem in order to pinpoint the relationship between toxins and AD.

b. Diagnosis of Alzheimer's Disease

Standardization of criteria and methods for assessing AD patients has been a major problem in diagnosing and evaluating the rate of deterioration in the disease process. One of the major achievements of NIA efforts in this regard recently has begun to bear fruit. As part of the congressionally-mandated patient registry program, a multi-center consortium

was created. It includes 20 participating institutions and is headed by Dr. Albert Heyman, a senior neurologist at Duke University. The consortium has developed standardized criteria and methods for neuropathological evaluation and diagnosis of AD brains; a standardized battery of neuropsychological test instruments, with translations of the test instruments into other languages; and a standardized method for evaluating the brain imaging data on AD patients. The consortium now has data on 700 patients and 700 healthy control subjects. This effort will, for the first time, allow both practicing physicians and scientists studying AD to have a standard set of tools and be able to compare each others' results.

The validity of such rigorous, standardized diagnostic criteria for AD has been demonstrated in the report of a longitudinal study of 26 AD patients followed to autopsy. Seventeen of the patients were diagnosed in the early stages of AD. In all 26 patients, the primary neuropathological diagnosis at autopsy was AD. While diagnostic accuracy rates as high as 90 percent have previously been reported, this investigation is unique in the inclusion of a large proportion of patients first diagnosed in the early stage of illness.

c. Treatment of Alzheimer's Disease

Recent advances in understanding the mechanisms of nerve cell function at the molecular level, and the development of sophisticated molecular genetic tools, have allowed unprecedented insights into human diseases such as AD. These developments have laid the groundwork for the introduction of functional genes into mutant cells in order to correct pathological cell functioning.

Using this approach, Dr. Fred Gage was able to genetically modify skin cells in culture to secrete NGF by infection with a retroviral vector. These modified skin cells were implanted into the brains of rats that had already experienced surgically induced brain dysfunction (a simple model for AD). The grafted cells not only survived these procedures, but produced enough NGF to stop the cell death that would surely have occurred without this treatment. This is a first step toward developing viable methods of treating AD and even preventing its progress. These results show that gene transfer and transplant technology may provide effective treatment of degenerative disorders of the brain thus extending its implications far beyond AD.

Research by two eminent neuroscientists, Dr. Carl W. Cotman and Dr. Dennis J. Selko, has shown that a fragment of the protein in neuritic plaques may possess the ability to regulate growth of nerve cells in the healthy human brain. On the basis of their experiments, these investigators speculate that plaque formation in AD may signal the nerve cells' attempt to mount a defense against the degenerative process and to compensate for the damage that occurs as the disease progresses. The investigators also speculate that events in the early stages of AD may lead to the production of an abnormal amyloid protein that malfunctions, thus contributing to the progress of the disease. Further understanding of these processes could well lead to new treatment strategies.

Many researchers are searching for drugs that will safely and effectively slow or reverse the symptoms of AD. NIA has also identified other potentially valuable drugs; we hope to start additional clinical trials within the next 6 to 12 months to test the following drugs: high-

dose thiamine, nimodipine, nerve growth factor, huperzine, acetylcarnitine, slow release physostigmine, and a combination of THA and clonidine. There is strong preliminary evidence to suggest that each of these drugs may have some effectiveness in treating the symptoms of AD. A test of one of these drugs, the multicenter clinical trial of the safety and efficacy of tetrahydroaminoacridine (THA), should reach a point at which conclusions can be drawn late in 1989.

d. Care of Alzheimer's Disease Patients

Progress is being made in developing a better understanding of the cause(s) of AD and finding effective ways to treat it. Nonetheless, until more advances are made, the disease will continue to present major challenges and burdens to AD caregivers, who for the most part are the families of the victims.

The burdens of care for AD patients are now well-documented. Knowledge about the burdens of AD on informal and formal care systems builds on a strong base of social, behavioral, and health research focused on the full range of chronic illnesses and disabilities in old age. Specific targeted research is needed to understand how this broad knowledge applies to the special burdens of care of AD.

The patient's changing state during the course of AD requires modifications of patterns of caregiving and creative strategies to reduce the burdens of care. A knowledge base for planned social, behavioral and technological interventions that can make a difference in the daily life of caregivers is especially needed. It is important to understand the nature of interactions between family care and more formal institutional and community services. Topics of high scientific opportunity are further

delineated in a forthcoming program announcement on "Alzheimer's Disease and Related Disorders: Issues in Caregiving,"—an effort coordinated among the NIA, the National Institute of Mental Health, the National Center for Nursing Research and the National Center for Health Services Research.

e. NIA Initiatives in Alzheimer's Disease

In 1988, the NIA awarded the first two Leadership and Excellence in Alzheimer's Disease (LEAD) awards. In January 1989 three more of these congressionally-mandated awards were made. The awards were made to scientists at Duke University, Harvard Medical School, Johns Hopkins University School of Medicine, University of California at Irvine, and University of Southern California. The LEAD awards are designed to strengthen the capabilities of outstanding senior investigators by providing up to 7 years of major funding support for their own research and for the development of outstanding junior investigators.

The NIA is also launching a major effort to inform and educate the general public concerning AD. The congressionally-mandated Alzheimer's Disease Research Centers and the developing Alzheimer's Disease Education and Referral Center are expanding efforts in educational activities for the public and for professionals.

Other NIA initiatives on Alzheimer's disease include development of a tissue bank as a resource for scientists studying the biology and genetics of the disease; and expansion of the NIA Alzheimer's Disease Research Center program with three new centers for a total of 15. In the area of international research, the NIA and the World Health Organization Special Program for Research on Aging developed a program announcement for proposals for worldwide crosscultural investigations on the epidemiology of AD and

other dementias of later life. There is suggestive evidence for significant differences in the frequency of AD in different ethnic and cultural populations which, if confirmed, may give clues to the cause(s) of AD.

In addition to NIA's extramural research program, its intramural laboratories are also active in Alzheimer's disease research, with studies on pathophysiology and diagnosis, and investigations relevant to assessing various clinical interventions. The Laboratory of Neurosciences, for example, uses highly sophisticated equipment such as the PET scanner which has demonstrated regional metabolic changes in the brains from Alzheimer's disease patients; this research may lead to early diagnoses and may serve as a useful guide for assessing therapeutic regimens.

National Institute of Neurological Disorders and Stroke (NINDS)

The study of Alzheimer's disease is also a high priority of the National Institute of Neurological Disorders (NINDS). NINDS-supported scientists are vigorously pursuing basic studies of brain and brain cell abnormalities associated with this dementing illness.

Dr. Joseph Coyle of the Johns Hopkins University School of Medicine in Baltimore, Maryland, is studying the mechanisms that regulate the production of acetylcholine, a brain chemical found at reduced levels in the brains of Alzheimer patients. Low levels of acetylcholine are linked to difficulties with memory, learning, attention span, and judgment—cognitive deficits that characterize AD. Dr. Coyle tested the drug galanthamine, which inhibits an enzyme that breaks down acetylcholine, to see if it improved memory in mouse models of AD. He found that administration of galanthamine before a swimming maze test greatly improved the ability of the mice to remember how

to solve the maze. Dr. Coyle's results suggest that galanthamine might be a useful agent for reversing certain cognitive deficits associated with the loss of acetylcholine-producing neurons.

AD is often difficult to distinguish from other cognition-impairing brain disorders. Yet early and accurate diagnosis is important in understanding and coping with the disease. Dr. Miriam Aronson, of Yeshiva University in New York City, is addressing this problem by outlining behavioral profiles of older people with Alzheimer-type dementia. Dr. Aronson found that such patients have greater difficulty recalling objects than remembering location. This finding, along with others that will complete the profile, may help clinicians to differentiate AD from other types of dementia.

Another diagnostic tool may be developed from an already available, often-used technology called the electroencephalogram (EEG), a non-invasive monitor of brain electrical activity. NINDS scientist Dr. Philip Sheridan reports that the EEG, which currently helps confirm the diagnosis of AD by ruling out other causes of dementia, may also be useful in indicating which brain regions are affected by AD in individual patients. Dr. Sheridan found a correlation among data on Alzheimer patients collected by three other NINDS intramural scientists: EEG recordings by Dr. Susumu Sato, positron emission tomography (PET) studies by Dr. Thomas Chase, and neuropsychological testing by Dr. Paul Fedio.

National Institute of Allergy and Infectious Diseases (NIAID)

Scientists from the National Institute of Allergy and Infectious Disease (NIAID) are investigating scrapie, a rare transmissible brain

disease of sheep and goats with degenerative lesions similar to those seen in AD. Scrapie is particularly important because there is no true animal model for AD, and it is possible that both diseases might be caused by similar infectious agents.

For many years, several intramural NIAID scientists—Drs. Bruce Cheesebro, Richard Race, and their colleagues—have been carrying out research on scrapie. The discovery in scrapie-infected tissue of large amounts of a particular protein, the prion protein (PrP), has led some scientists to propose that PrP causes the animal disease.

Experiments have shown PrP to be a normal endogenous protein of brain, and probably other tissues as well. But scientists have also found that during scrapie infection, a modified form of PrP accumulates in the brain. It is not known whether the modification occurs as an insignificant result of the disease or if, in fact, the modification changes PrP from being harmless to infectious. Some scientists have suggested that the alternate form of PrP may, in fact, be the transmissible agent and the cause of scrapie. It is possible that a modified form of PrP is the disease agent or a component of it, or that PrP may be indirectly involved in causing disease.

Division of Research Resources (DRR)

Grantee Dr. Gary Small found that the antigen, HLA-A2, was present in a group of men who developed AD before the age of 60. These results indicate that blood tests for the presence of HLA-A2 may help identify men who are susceptible to early onset AD. While the cause of AD is unknown, some studies indicate that it progresses more rapidly in people who develop it

before age 60. The researchers believe that HLA-A2 may be helpful in identifying more homogenous subgroups of patients with AD. This in turn may help identify possible approaches to therapy that would lead to specific treatments.

ALCOHOL, DRUG ABUSE AND
MENTAL HEALTH ADMINISTRATION (ADAMHA)

National Institute of Mental Health

Research in the area of Alzheimer's disease and related dementias and the mental disorders of the aging represents a major programmatic effort of the National Institute of Mental Health (NIMH), an institute of the Alcohol, Drug Abuse and Mental Health Administration. A substantial commitment has been made to support Alzheimer's disease research, using the approaches of the basic and clinical neurosciences, the behavioral sciences, and health services research. This research is carried out by NIMH scientists in the Institute's intramural research program as well as by investigators whose work is supported by NIMH grants. NIMH Alzheimer's disease research includes nearly all aspects of the disorder, ranging from basic studies of potential etiologic factors to evaluations and cost-effectiveness studies of promising models of delivering services to patients with Alzheimer's disease and their families.

In terms of the etiology and pathogenesis of the disorder, these include studies of basic mechanisms of memory and learning, as well as the neuroanatomy, biochemistry, genetics, electrophysiology and neuroradiography of the disease. For example, Dr. Leonard Heston at the University of Minnesota is establishing lymphoblastic cell lines on all available members

of a number of large families affected by AD. These tissue samples can hereafter be used as a permanent source of DNA for future studies of the family genetics of AD, using new techniques which have yet to be developed.

A number of the NIMH grants on basic and clinical aspects of Alzheimer's disease have diagnostic implications, and have been awarded to investigators searching for potential biological markers for the disorder. In one line of research on a suspected marker, Dr. Peter Davies at Albert Einstein College of Medicine is studying an abnormal protein called A-68, found in the brains of AD patients. In another set of studies, Dr. George Zubenko at the University of Pittsburgh has identified a blood platelet abnormality in these patients, namely increased fluidity of platelet membranes, which is hypothesized to be a product of genetic factors in AD.

Research has also been directed toward identifying electrophysiological (EEG) and radiological indicators that may have diagnostic utility in AD. In studies of sleep in AD patients, NIMH-supported investigators such as Dr. Patricia Prinz at the University of Washington and Dr. Charles Reynolds at the University of Pittsburgh, have identified EEG sleep patterns that aid in diagnostically differentiating early Alzheimer's disease from depressive disorder in elderly patients. Other scientists, like Dr. Ajax George at New York University and Dr. Andrew Leuchter at UCLA, have utilized multiple neuroimaging techniques and computerized EEG analysis to delineate additional signs of brain structure and activity that can assist in diagnosis.

NIMH's intramural program in geriatrics focuses on evaluation of various potential psychopharmacological treatments for Alzheimer's patients.

NIMH also supports a number of investigator-initiated studies directed toward developing better psychopharmacologic and behavior techniques for managing the characteristic symptoms of Alzheimer's disease. Work along these lines is currently being conducted by Dr. Jerome Yesavage at Stanford University, Dr. Pierre Tariot at the University of Rochester, and others.

NIMH support for basic science research relevant to Alzheimer's disease is also strong. Although this type of research tends not to be focused exclusively on Alzheimer's disease, it is very important for improving our scientific understanding of the pathological processes in this and related brain disorders, and for developing more refined research methods that may assist in uncovering their basic cause.

NIMH recognizes that services research on Alzheimer's disease needs to be vigorously increased, and has made programmatic efforts to encourage more investigator-initiated grant applications in this area. NIMH has issued an RFA for "Research on Family Stress and the Care of Alzheimer's Disease Victims," focused on treatment and family support of Alzheimer's patients and their family caregivers. In support of this research initiative, NIMH is publishing a manual, entitled "Alzheimer's Disease Treatment and Family Stress: Directions for Research" that will be available later this spring.

There is preliminary evidence that the stress of caregiving is associated with impaired immune functions and may have long-term health consequences. NIMH is currently funding several grants that bring the recent technological advances of psychoimmunological research to bear on caregiving, with a focus on the chronic impact of caregiving on immune functioning and psychological distress. These studies, such as the work of Dr. Janet Kiecolt-Glaser at Ohio State University, are exploring whether

neuroendocrine and immunologic factors may help distinguish successful from unsuccessful caregivers, and may predict which individuals will themselves develop an illness under the stress of caregiving.

In other family-oriented studies, clinical researchers like Dr. Dolores Gallagher at Stanford University and the Palo Alto VA Medical Center, are designing therapeutic interventions to support family members in their caregiving role, and to treat those troubled by symptoms of depression, anger or anxiety. Additionally, NIMH is funding several service delivery demonstration projects that are evaluating the impact of model service programs on patients and their family members.

NIMH expects that its current efforts will stimulate additional fundable research on basic neurobiological mechanisms of the disease, diagnostic profiles, approaches to the characterization and management of the behavioral and psychiatric symptoms of Alzheimer's patients, and research directed toward new models of family care and service delivery for this disorder.

Conclusion

The work of the DHHS Council on Alzheimer's Disease, the Advisory Panel on Alzheimer's Disease, and the NIH-wide Alzheimer's Disease Coordinating Committee has very effectively coordinated the efforts of the Department and the Veterans Administration in their collaborative focus on Alzheimer's disease. Research to date has brought us considerably closer to unravelling the mystery surrounding the cause(s) and cure for Alzheimer's disease. But the cause is still unknown. Clinical studies have led to some progress in alleviating some of the excess disability of Alzheimer's disease, but there

still are no treatments that can prevent, cure, or halt the progression of this dread disorder. Meanwhile, with the rapidly expanding number of older Americans, the prevalence of Alzheimer's disease continues to rise by alarming numbers. Research remains our best hope for ultimately reducing the terrible impact of this disorder on patient suffering, family burden, and societal costs.

Mr. Chairman, I will be pleased to answer any questions you or the other members of the committee may have.

The CHAIRMAN. Thank you, Dr. Williams. I will start off the questioning of the witnesses and then I will yield to members of the committee. We hope that each one of us will take 5 minutes, then we will come again for another series of questions.

My first question is to Ms. Nancy Lombardo. Ms. Lombardo, you expressed the thought that the centerpiece of a Federal commitment for Alzheimer's disease would be to establish a research goal of \$500,000,000 by 1992. That is what we are attempting to do in the legislation that is being introduced today.

But I am concerned about another aspect, not just the research, but the services that must be provided to families who care for Alzheimer's patients at home.

You stated that it costed in excess of \$400,000 to take care of your mother. What can the Federal Government do to provide such a service? Do you have some recommendations that you can make to this committee?

Ms. LOMBARDO. Certainly. In my own family's case, we were very lucky and my father was able to hire a woman to help take care of my mother in the home. But having now years of experience with other Alzheimer's families, I know that was a rare experience.

Both the Federal and the State government can help stimulate the availability of support services and then help families find the means to afford them.

Families need a variety of help. At the outset, they need information and counseling. Our chapters can do a lot in that regard but there needs to be coverage statewide, nationwide.

Eventually the family, whether it's an elderly spouse, such as in Richard's case or a younger spouse as in my father's case, they need help in the home.

I didn't mention it but my mother-in-law was just diagnosed late last year with Alzheimer's disease so now my second mother is also afflicted, and my father-in-law, who is 79, is really having terrific difficulty coping with my mother-in-law's illness.

He needs all sorts of help. He is now doing all of the cooking and the cleaning, as well as the personal care of my mother-in-law. He needs help in the home, such as chore services, respite care, adult day care—whether its someone to come and watch my mother-in-law once in awhile so he can get out and take care of personal business, whether it's day care so that he can take my mother-in-law to some place where she can get some activities and social therapy—he needs Meals-on-Wheels so that he doesn't have to take care of all of the cooking. There is a wide array of services that could help ease the burden.

In each case, the providers of those services need proper training. My father-in-law could use some instruction so he knows what he's dealing with. I've tried to help him the best I can, based on our years of experience, but many families wouldn't have that case where the daughter-in-law has already lived through this with her own mother. So there are just a whole variety of programs that can be stimulated through the Federal Government and through the States.

The key is financing. Most families simply do not have the financial wherewithal, even if these programs were available, to pay for them. Even when the costs may be modest in the home, people are

afraid to spend what little savings they have because they know down the road they might be facing the high cost of nursing home care. We need Federal long-term care insurance.

There are just many things that need to be done, whether it is services in the home or in the nursing home, and improve those services in nursing homes.

Unlike Richard's experience, my mother's experience in a nursing home has been fantastic in that I've never seen anything wrong in this home. They take excellent care of her. She wouldn't have lived there for 14 years if they weren't doing everything right.

She has never had pneumonia or a bed sore and that is very rare. Every home needs to be a model nursing home with the staff properly trained to take care of dementia patients.

The CHAIRMAN. Thank you.

Mr. Moll, again quoting from your testimony, you said in reference to your mother that "She became a virtual prisoner in her own home," and I've seen that happening time after time.

But then you asked the question, "Why did she have to do it?" Then you went on to say, "Well, because of public and professional ignorance of Alzheimer's and related diseases."

You also hit another important point. You said, "Because of a real lack of services available for families caring for Alzheimer's patients in the home."

Then you went on to say, "Because of a serious shortage of nursing homes specializing in the care of Alzheimer's patients."

Now, those are the things, Mr. Moll, that we are proposing to do in the legislation that we are introducing today.

My question to you: How do you think that the Federal Government, together with the private sector, can actually help the financing of these services?

Mr. MOLL. I don't know, Mr. Chairman. I wish I knew. I wish I knew a little bit more about the in's and out's of Government and financing to answer that question in a way that would be—all I know is what I feel the end result needs to be.

I think the most important thing of those three is to have those personnel properly trained, and I would like to see nursing homes that specialize only in Alzheimer's. I would like to see more of those, because my mother still lives, and my parents did live, in Placerville, California.

It is a small town, as you know, in the Sierra foothills, about 35 miles from Sacramento, and there was really no nearby facility, both day care and the nursing home that he ended up in, that really, really knew how to deal with this disease. So I think it is important, the training, of the personnel who help to provide the in-home services.

And even more so, I think the patients wouldn't be at home as long as they are if people knew that there was place where they could take the patient where they would be treated properly, not just a place to go and die, just a place to fob off, just some place where they are going to go and perish, some place where they would feel good about leaving that spouse, that relative, where they would know that he was going to be cared for as an Alzheimer's patient should be cared for.

I would love to see a proliferation of homes specializing in the treatment of Alzheimer's patients or at least see homes that have a wing devoted to that or a certain area of it that is devoted to the specialized treatment and care of Alzheimer's patients. Thank you.

The CHAIRMAN. Mr. Moll, I think you are absolutely correct, that something like that can be done, and it has been done in other countries, not necessarily with regard to Alzheimer's disease, but I agree with you that because of Alzheimer's, we are still in the Dark Ages.

But we are in the Dark Ages insofar as health is concerned in general. We are not number one in the delivery of the health system in the world. We are far behind. There are other countries throughout the world that are doing a much better job.

I don't say that they are perfect, but I believe that if we take those things that are good in each of those countries and then establish in this Nation a national health plan, that we will be able to take care of this particular situation.

We are one of two industrialized nations in the world, South Africa is one and we the other, that does not have a national health plan.

No one really knows the answer. You are right, I don't know, and that is what we Members of Congress say, "We don't know," but there are people that do. We must do more work, I believe, in finding out what the answer is, what other nations are doing and start doing the same thing here in the United States.

I would like to, at this time, just go beyond my 5-minute limit and then give equal time to the other Members.

Mr. Moll, I would like to tell you about something that I'm going to try out. We have established, at Cal State in Los Angeles, a gerontology center. It is going to be called the Roybal Gerontology Center. There are 10 gerontology centers throughout the Nation today, a little bit more than that.

There will be 20 by the year 2000, and the gerontology center at Cal State will be the only one that will be community-based because it is applied gerontology. We are going to take the knowledge that we get from other research and other universities and apply it to the community in East Los Angeles, making it possible for those who care for patients in the home to get training, to get assistance, and do the various things that have been recommended by both you and Ms. Lombardo.

It will be on a trial basis, no doubt—well, maybe not a trial basis but a demonstration basis. We will demonstrate to the official agency that it can be done. Then after that demonstration takes place, I hope that we can pass something in this Nation that will provide those services and will eventually find a cure or prevention for Alzheimer's disease.

Mr. Moll, I wanted to ask you and Dr. Williams some questions but my time has expired. I will come back to both of you and ask you some questions.

I would like to discuss with you, Mr. DeLay, AARP's program with regard to long-term care and with Dr. Williams other matters of great importance.

The Chair now recognizes Ms. Schneider.

Ms. SCHNEIDER. Thank you, Mr. Chairman. I might take the liberty of responding on your behalf, Mr. Moll, to the question that the Chairman had asked you about how you feel the Federal Government could best serve those needs.

One of the things that I find very frustrating, in that I not only serve on this committee but I serve on the Science Research and Technology Committee, is to acknowledge the enormous imbalance that this country has seen in terms of where our research dollars go today.

Prior to 1980, between 1965 and 1980, we had about a 50-50 split between research in commercial areas, which included health, disposal of hazardous waste, environmental concerns, industrial competitiveness—a whole broad spectrum of things. Fifty percent was in the commercial sector, the other 50 percent was in defense.

Now, our budget disburses 73 percent of the research dollar toward defense and the remainder among all of these health concerns, and every other research that is being done in the United States. I know that it was mentioned a little earlier that any individual would be willing to have their taxes increased to pay for health care—I think that it is important that we not look at health care in a vacuum but recognize how the whole big system works.

The AARP and other senior organizations can have a valuable role in making sure that we get our Government priorities set as a whole and if we feel that we ought to have 50 percent military and 50 percent commercial, then we certainly do have to lobby in that regard and not just lobby solely for this legislation or other bits and pieces. There is a bigger picture that we have to comprehend and work toward, because granted, if we don't reduce this deficit, the cost of health is not only going to double, it's going to quadruple.

We have to keep our eye on that bottom line on reducing the deficit overall so that while we are spending more money here, the inflation rates aren't going up somewhere else, and that is how the whole system balances.

So I would encourage each and every one of you to make sure that you do support the legislation to get a balance toward the commercial versus military sector of research.

The other thing I would like to ask Dr. Williams—you were mentioning about the research into the diagnosis of Alzheimer's disease patients. You mentioned that we can now diagnose Alzheimer's disease but that's through autopsies, so that means we have to wait until the person is dead. How are we doing diagnosing it prior to death?

Dr. WILLIAMS. Yes, Congresswoman Schneider. I meant to emphasize that. This effort has included our conducting a consensus development conference on the differential diagnosis of dementing diseases about 2 years ago. That conference, plus considerable effort in the Alzheimer's Disease Research Centers and other settings around the country laid the groundwork for clinical diagnosis.

The ability to make the clinical diagnosis of Alzheimer's disease was 100 percent in one reported study. It is probably now better than 90 percent overall when the clinical criteria are carefully used.

In this study, which came from St. Louis just a few months ago, the investigators made the clinical diagnosis carefully and then followed a group of patients to autopsy. They were 100 percent accurate as ultimately judged by autopsy. So you could say that we now have the clinical capabilities for making the diagnosis, if we are careful in doing it, which we can feel confident will correspond to ultimate autopsy finding.

Ms. SCHNEIDER. Well, that is very impressive because just 2 short years ago, we were not in that state of affairs, but you find the 10 percent of your funds being used to disseminate information to be adequate?

Dr. WILLIAMS. I think that we certainly need to expand our efforts in dissemination, and we will be expanding them this year with the Alzheimer's Disease Education and Referral Center, which Congress mandated a little over a year ago. It is in the developmental stage and will begin operating this year. The center will be a real clearinghouse for all types of information.

Information dissemination of Alzheimer's disease research, is a very important aspect of our mission and I'm confident it will receive more attention. It's not just a matter for the public and caregivers; professionals must also be up to date on what we know about this disease.

Ms. SCHNEIDER. Is my time up, Mr. Chairman?

The CHAIRMAN. One more minute.

Ms. SCHNEIDER. Another question I had wanted to ask was that in the legislation that we are discussing there are provisions of \$25, \$26 and \$28 million between 1990 and 1992 to support joint research and demonstration projects into family stress that results from caring for an Alzheimer's victim.

I am aware that there is an enormous amount of research going on right now on stress, stress being caused by a variety of different ways. But to make sure that we are focusing and setting our priorities appropriately, do you really believe that we need those kinds of monies to do research on how stressed out people are in dealing with the families, or wouldn't that money be better spent in terms of doing research for a cure or perhaps supplementing the caregivers or transferring information, as you are doing, about care?

Dr. WILLIAMS. What we have, in my judgment, is a need in all of these areas. We have far more good applications for careful studies about the role of stress and how it impacts on caregiving and, therefore, on the survivability, if you will, of the caregivers than we can fund now.

I brought along a list of just a few of the projects that are currently funded. I can read a few of the titles, if I may. "Coping with Dementia." "Stress in Alzheimer's Patients." "Spouse Interactions." "Cost Benefit of Easing the Burden of Alzheimer's Caregivers,"—that is, the evidence that by easing the burden there will actually be cost savings because it minimizes other more expensive care. "Enhancing Caregivers Capacity to Care for Frail Elders," is another example, and I could give others.

In my judgment, there is no question that this is an important area. It is, however, always a matter of balance, given restricted resources, how we would try to weigh them. I wouldn't want to be

locked into a specific figure about that balance, but I think that basically, we certainly could benefit by more research in this area.

Ms. SCHNEIDER. I thank you and all of the witnesses for your great insight into our challenges that we face. Thank you for appearing here today.

The CHAIRMAN. Thank you, Ms. Schneider. The Chair recognizes Mr. Pallone.

Mr. PALLONE. Thank you, Mr. Chairman. A couple of the issues about which I was most concerned were already touched upon, but I wanted to ask about issues related to the diagnosis of Alzheimer's disease.

One of the suggestions that was made in New Jersey as the result of a commission report, in 1986, was that there be diagnostic centers established, either a few in the State, or I suppose we could have many throughout the country.

I have the impression that many times when you have to go to an individual doctor, a local practitioner, even a local specialist, that it may be less likely that an accurate diagnosis will result. To what extent would it help to create regional diagnostic centers to properly identify Alzheimer's disease? I imagine this legislation would cover some of that, but I wondered to what extent that is being done.

Dr. WILLIAMS. It requires a careful and sophisticated, well informed workup to be sure about the diagnosis of Alzheimer's disease. One of the problems in the past, Congressman Pallone, has been that the workup has often not been adequate. It has been all too common that a physician would do a rather superficial workup and say, "Well, it looks like senility," or "It looks like maybe Alzheimer's disease and there's not much we can do," when, in fact, in 10 to 20 percent of instances there are treatable disorders causing a mental impairment. It is really a tragedy to miss something that is actually treatable or correctable now. I think there is no question that it calls for a careful workup by someone who is fully informed.

We have widely circulated the summary of the consensus conference on "Differential Diagnosis of Dementing Diseases." It has been circulated through the Journal of the American Medical Association and in many other ways. The aim is to reach all physicians. Nevertheless, in fact, I think that in most instances it probably would be wise that a patient who has developed some signs of mental impairment be referred to a specialist who is really able to use all of the necessary resources.

This calls for some specialized x-ray studies, specialized neurologic examinations, and specialized psychological testing, as well as other tests, just to be sure. So I think it is the type of diagnosis that should be confirmed in a setting that is capable of doing the whole job. That will typically be a multi-specialty group practice or a hospital with these capabilities or a specialized center.

I think that some provision for paying the cost of a workup is needed. The workup probably costs \$500 or so. That would be a gross estimate, but it is easily worth that.

Mr. PALLONE. Are we providing in some way through the Federal Government for these type of centers or specialized regional groupings of doctors so that that is available?

Dr. WILLIAMS. Not specifically, to my knowledge. Our institute supports 12 Alzheimer's Disease Research Centers and we will be adding three more with funds available in this year's appropriations to make a total of 15. They are scattered around the country, but are not within easy reach of everybody, by any means; but they can certainly do this type of job.

We support a number of other sites with program project research funds which are also capable of this work, but it's the type of thing, in my judgment, that a typical sizeable community should have as a resource in its own community hospitals, or in a similar setting.

The regular mechanisms of payment will cover these costs for the most part, as far as I know, but there would be some advantage in trying to assure a level of quality. It would be worth considering a single charge, if you will, a reimbursable charge for a complete workup.

Mr. PALLONE. I know Mr. Moll mentioned that there is often a lack of specialization or knowledge about Alzheimer's in some nursing homes. One of the suggestions that I heard, and I don't know whether it is being done, perhaps you could comment on it, is to simply have some sort of guidelines. I guess they could be Federal guidelines or something established on a Federal level—I know some States have toyed with this—for nursing homes in terms of treatment of Alzheimer's victims.

Is that being done now or is that something that has been suggested?

Dr. WILLIAMS. There are new guidelines just now being issued by the Health Care Financing Administration in the Department of Health and Human Services, for maintaining and improving the quality of care in nursing homes across the board. These are being actively reviewed and commented on.

I might just add that my wife, who is a social worker, is very actively involved in trying to achieve highly individualized, restraint-free care in nursing homes, along the lines of some of the problems that were cited before.

There is a lot of effort going on in this area and there are Federal guidelines that are moving to address some of these issues in general. I believe these guidelines, if they are well carried out, would cover the needs of Alzheimer's patients as well as others.

Mr. PALLONE. There isn't a need though for treatment guidelines specific to Alzheimer's.

Dr. WILLIAMS. They certainly need to be explicitly covered in these guidelines. I think that the intent is that they will cover any form of dementia explicitly when that's part of the problem. A loss of mental function would cover Alzheimer's as well as other causes; not only those conditions, but others.

I think the question of specialized units is of a great deal of interest and certainly this is a direction to consider moving in, either as a specialized unit within a nursing home or perhaps specialized nursing homes. On the other hand, there are people who feel that a mix of patients is healthier. It depends on the condition of the patient. I believe we will see more efforts to understand just how to do these things better.

Mr. PALLONE. I guess you are going to return again for another round of questions, so I will wait.

The CHAIRMAN. That is correct.

Mr. PALLONE. Thank you, Mr. Chairman.

The CHAIRMAN. The Chair now recognizes a young lady that is also new to the committee. She also expressed a desire to be a member of this committee last year. I would like to welcome her at this time and yield the floor to her. Ms. Jolene Unsoeld of the State of Washington.

Ms. UNSOELD. Thank you very much, Mr. Chairman, and members of the committee. I wanted to really use this time to thank the witnesses for their presentation today because there is certainly a wonderful body of information. I want to particularly thank Ms. Lombardo and Mr. Moll for the other sharing that you did for us because the kind of disproportionate research funding that Congresswoman Schneider talked about, and others, if we are going to make that break and re-shift our priorities, our national priorities, it has to come about because the public and the elected officials don't just have good data, don't just treat this problem and these people like things but because they feel, and you have helped to make us feel. For that, I thank you very, very much and we will try to translate that into some action. Thank you.

Mr. MOLL. You are welcome.

The CHAIRMAN. The Chairman now recognizes Congresswoman Morella.

Ms. MORELLA. Thank you, Mr. Chairman. I really appreciate your calling this hearing today to examine the problems facing Alzheimer's disease victims and their families and the progress that is being made in Alzheimer's disease research.

It is certainly clear that Congress must expand the Federal support for research efforts to prevent, treat and cure this devastating disease. I am again delighted to be a cosponsor of your legislation, the Comprehensive Alzheimer's Assistance Research and Education Act, the CARE bill.

Its 3-prong focus on research, education and family assistance would go a long way in achieving our research objectives, educating the public and providing relief to the families of Alzheimer's victims.

I hope that the hearing today will help to further clarify the current priorities and assist us in finding some solutions to it. This is what I perceive as the biggest need of the constituency that I represent and I'm sure it's true of all of the Members of Congress.

I would also like to welcome Dr. Williams. I welcome all of the panel but I happen to know what Dr. Williams has been doing in this area and I welcome you, and Dr. DeLay, Mr. Moll and Ms. Lombardo.

For Ms. Lombardo, of the Alzheimer's Association, as you probably know, there is strong support in Congress for increasing the funding for Alzheimer's programs. Can you give this committee a priority list, whether you have it now or whether you would submit it for the record?

We want to know if we should focus first on research into a cure, which may still be many years away, or should we concentrate on resources, on care for those afflicted by the disease, or should the

support be given to the caregivers? We have so very much to do; we have limited resources, and to get some advice from experts would be very helpful to us as we choose the best avenue.

Ms. LOMBARDO. I don't think I can give you an easy answer. I don't think it can be either/or. I think we have to go after more research or we will never solve this problem. If we don't solve the problem, the cost of care by the families will just get bigger and bigger, so we cannot do without research.

At the same time, we have to start developing services in the communities that will help us take care of the patients that we have now, and we have to start on long-term care legislation to see that this disease doesn't bankrupt families.

Ms. MORELLA. Should there be equal emphasis given on those various areas?

Ms. LOMBARDO. The problem is that research actually costs a lot less than services, so I think actually \$500,000,000 is a rather modest investment in trying to take care of this disease. I think that just has to be done. Services are very expensive.

I think we can start with innovative services through the kind of matching grant program that is in this bill. Then I think the long-term solution is, as my friend here from AARP has said, we need Federal social insurance for long-term care.

We must have that, and with everyone in society contributing to it. The money then wouldn't all come from Federal taxes or the Federal Government; the cost would be shared across society. We must do that as soon as possible.

That is the only long-term solution to the service needs. That will stimulate the creation of services, that will bring about proper training of providers, if that is required, in this type of legislation.

Ms. MORELLA. And include relief for the caregivers too, who are often the family members that are just so overwhelmed with the enormity of their responsibilities.

Ms. LOMBARDO. Right. I wanted to add to Ms. Schneider's question about the need for research on caregiver's stress. If we are spending over \$80 billion already on services, we need to know how to target services to people.

It is well known that whether a person has a family or not is going to really determine how quickly they end up in a nursing home. If we understood better what helps the family member hang in there so we could target the limited resources we have to help them, I think it is well worth the modest investment of a few more million dollars.

Ms. MORELLA. We have a lot of heroes who have been caregivers—one who is a constituent of mine, Mr. Chairman, whom I met probably about 8 years ago, who had to leave his job at NIH to take care of his wife, who became the subject of a documentary which won an award, and now several documentaries, who is now involved in our State of Maryland on a task force that the governor has established—you probably know him.

Ms. LOMBARDO. Glen Kirkland.

Ms. MORELLA. Glen Kirkland, right. He has been such a profile in courage and he represents the other family members who are also profiles in courage in terms of what they have done.

I also see someone from my county who is with the Alzheimer's and Related Disorders Commission.

Could I just ask one other question? How do these organizations all fit together? Do we have duplication of energies and efforts? Is there some way that the various Alzheimer's organizations come together?

Ms. LOMBARDO. First of all, there is really only one national Alzheimer's Association and that is our organization. We have nearly 200 chapters. On the local level, you find our chapters working with providers and other groups that are concerned about this problem, whether it's nursing homes or homes for aged or hospitals, so there really is a way of linking together.

Almost every State that has a task force on Alzheimer's disease—there are over 30 States that have had task forces—that brings together people from all over the State that are interested in this problem. There is a lot of collaborative efforts now and we need to keep that going.

Ms. MORELLA. But there is no friction or problems?

Ms. LOMBARDO. Not that I am aware of.

Ms. MORELLA. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Ms. Morella.

Mr. DeLay, I said I would come back to you with a series of questions with regard to AARP's long-term care program. As you were describing it, you were actually describing a bill that I introduced 3 years ago, which still hasn't been acted upon, and that is a national health plan.

I don't know whether the AARP has taken a position with regard to a national health plan or not but that is not the issue at this moment. But I would like to ask you on a personal basis, were you actually describing a national health plan when you described what you included in a long-term care package that AARP is supporting?

Mr. DELAY. Well, AARP is interested in the establishment of a national health program. What I was describing is just one aspect of long-term care, which is one of our major commitments. We hope that Congress will be able to give attention to the things that I listed here for the establishment of long-term care. I feel that it is vitally important.

We are very greatly concerned about the impoverishment of individuals who have to go into bankruptcy. I had an associate whose husband had Alzheimer's. She was not financially well off and she declared bankruptcy in order to be sure that her husband could get nursing home care. These are the types of things that we are interested in, sir.

The CHAIRMAN. Mr. DeLay, again, I am going to ask you a question that is hard to answer because I don't think that anyone really knows the answer, but we know how to get things done in many ways. But the question is, how can Congress build the political will necessary to establish a long-term care program?

Mr. DELAY. Our research indicates that there is much more interest in a social insurance program, which builds right into that, than there is in a welfare program. As I pointed out, over 60 percent of the people responding to our questionnaire, our research, indicated that they would welcome paying more money in taxes if

that money were directed toward the establishment of protection from long-term problems.

The CHAIRMAN. What I would like to see, Mr. DeLay, is this constituency that you are talking about, these people that answer the questions, I would like to see them start an active program prevailing upon the Congress of the United States to pass a long-term care bill. Now, that hasn't happened yet.

I don't know how many members there are in your organization and the other senior citizen organizations combined but I can assure you that such an army could definitely change opinions on Capitol Hill.

My constant advocacy is one of action and that is that I am hoping almost every day that a program would start where people in the United States would write just two letters a year, one to the President of the United States and the other to their own Congressman, asking them to support a long-term care bill. I think, Mr. DeLay, that that would make a difference.

It needs an organization like AARP and other groups to actually push it and support it and I hope that somewhere down the line we can get that kind of coalition together, so that those who have experienced Alzheimer's firsthand, like Mr. Moll, Ms. Lombardo and the rest of us, can be joined by others who will actually start pushing so that the Congress of the United States can pass this piece of legislation.

The political will question has been asked on many occasions and I hope that we can start thinking more about how that can be done.

Dr. Williams, I would like to ask you some questions with regard to your testimony. In your written testimony you state that there are approximately 3,000,000 people over 65-years of age with Alzheimer's disease. Am I correct that the number of victims is really much larger and actually close to 4,000,000 victims? What does this mean for both our Federal research and long-term care policy?

Dr. WILLIAMS. The more carefully we have conducted studies to identify people with even early changes of mental function, memory loss, the larger the numbers we find.

There are studies which will be reported shortly, that I think certainly point to larger numbers, including people with very early changes. I think that the chances are very high that as we do more careful studies, we are going to find that the numbers are probably closer to 4,000,000 than to 3,000,000.

An even more critical point, in my judgment, is that given the fact that the frequency of this disease rises rapidly in very late years, beyond age 85, and the fact that we will have a doubling of our population age 85 and over between now and the turn of the century, from about 2,500,000 people now to over 5,000,000 by the turn of the century, the numbers are bound to increase. We can expect almost a doubling of these figures by the turn of the century.

Now, whether we are right about a figure of 3,000,000 or 4,000,000 now, it is going to be 6,000,000 to 8,000,000 by the turn of the century in this country.

The CHAIRMAN. Dr. Williams, I was very interested in statements made when I visited you just a week ago, where I was told that

sometime before the end of the year an announcement will be made about a breakthrough, not a cure, not a vaccine, but some advancement in Alzheimer's research. Will you give us hope again as to when that will come?

Dr. WILLIAMS. One announcement I did include in my spoken testimony now. As of last Friday, on the 17th, there was an article in the journal, "Science," which we were not at liberty to speak about publicly until it was published. This article presents very interesting evidence that a portion of the protein that makes up the amyloid deposits—the deposits that we have thought were part of the damage in Alzheimer's disease—have now been shown to have nerve growth promoting properties; i.e., that it probably is a normal growth factor, one more growth factor for normal nerve cell function.

It is suggested that what may happen is that as damage occurs—and we still don't know the cause of the damage—this protein may be over-produced to try to correct the damage, but it ends up just being deposited there.

Now, there are several very promising things about this. One is that it gives us an entirely different insight about one of these critical proteins in the disease and it may well be that this protein, when used in proper ways, will help to reconstitute or help in re-growth of damaged nerves. So this is one more clue to several factors that it may be possible to use to restore or replace damaged nerve function.

As I mentioned, nerve growth factor has been administered to small animals with experimental brain damage, with unequivocal improvement. The steps now will be to test it in larger animals. If it seems safe and effective, the aim will be to move on to testing nerve growth factors in human beings with Alzheimer's disease, with some reasonable hope that it might correct this disorder.

The CHAIRMAN. Dr. Williams, the present level of funding for Alzheimer's research at the present time is approximately \$120,000,000.

Dr. WILLIAMS. Yes, sir.

The CHAIRMAN. The bill that I am introducing today will be increasing that to \$500,000,000 by the year 1992. With this increase, what areas of research would you be able to implement which are not currently being done?

Dr. WILLIAMS. Right now we have many research opportunities that extend beyond our current funding ability. We are making exciting progress in many areas and it shows that the field is ready for further growth. This applies to many areas of research.

The administration has to face the facts of the many demands on funds, but I think in this area if there were more funds available, we would certainly expand our research on basic causes of the disease, the mechanisms that produce the disease, the possibilities for intervention, and for prevention, as well as correction and treatment.

We could refine our diagnostic abilities even further. There are potential tests—it might be an objective chemical test—to really confirm this diagnosis even more definitively in life. Also, we would certainly be able to extend our work on understanding what the best approaches to caregiving are and to the dissemination of

information. The whole range of activities related to Alzheimer's disease deserves as much attention as we can all afford to give it.

The CHAIRMAN. I firmly believe that the \$500,000,000 that is in the bill is just a starting point. The bill in question, as you know, does, in fact, fully fund the present 15 centers. It also funds research into cause, prevention, diagnosis, treatment and management of Alzheimer's disease.

We go beyond that in this bill. We ask and place funds for training health care personnel, which I think is most important. Most of our youngsters are not going into the health field anymore. They are going into other more lucrative positions.

Dr. WILLIAMS. Yes, sir, that is very important.

The CHAIRMAN. We also put money in the budget for disseminating clinical information, conducting community education on Alzheimer's disease, which is very important and hasn't been done. We also provide funds for coordinating with other centers and related public and private facilities throughout the country.

The dissemination of information is most important, but then the use of this information to be applied to the community is even more important than that. So in this bill when it is enacted, I think we will have in place a very good start.

Dr. Williams, again based on what you know about research in other disciplines, do you agree with me that \$500,000,000 is just a start?

Dr. WILLIAMS. I think that is a reasonable start. I might just add, as I think many staff members know, and as members of the Department know, the Alzheimer's Disease Advisory Panel in its recommendations is going to recommend \$300,000,000 now for increased research in Alzheimer's so it's in the same general range as your proposal.

The CHAIRMAN. Well, the problem is, of course, that the authorizing committee may authorize the full amount. But then when it comes to the Appropriations Committee, we have problems there. We have problems funding the full authorized level.

However, I think if priorities are changed just a little bit, that we can do it and we hope that we will be able to do it in this particular instance. We still have a long way to go but there is hope.

Progress is being made in research and I hope that at least next year, when we look back on what we did today, we will find that we are making progress in some of the other disciplines, particularly the caring for those individuals who care for Alzheimer's patients at home. I think that is the key to long-term care in the most inexpensive—not inexpensive, but less expensive situations.

The Chair will now recognize Mr. Schuette.

Mr. SCHUETTE. Thank you very much, Mr. Chairman. I am quite interested in this hearing that you have proposed today, even though I'm late, because of this issue that impacts people all across our country.

I certainly think it is very important that you held this hearing today. For our panelists and distinguished group here today, thank you for sharing your thoughts with us.

I will spare any further comment and I will reserve my questions for a later moment in time, if I may, Mr. Chairman. Thank you.

The CHAIRMAN. Thank you, Mr. Schuette. Mr. Pallone.

Mr. PALLONE. Thank you, Mr. Chairman. I certainly agree with what you said about the need for a long-term care program and I think that needs to be focused in on, certainly in terms of trying to get support for it nationwide.

I just wanted to go back briefly to the day care question because just from what I've seen, it seems that day care programs really are very beneficial. I happen to have visited one several times in my own district that is called the "Our House Adult Day Care Program," at Monmouth Medical Center.

I was really impressed not only by the quality of care, but just by the fact that the patients just seemed to be so happy. We know, of course, that Alzheimer's disease is irreversible and people are not getting better because they are enrolled in any particular program.

But I just had the impression at this day care program that even though there wasn't progress per se, just the fact that people were in a setting where they enjoyed being and there were smiles on their faces, it just gave me the impression that something important was happening there.

Even beyond that, just the fact that caregivers can take a relative or someone that they are caring for to a day care program, either a few days a week or even 5 days a week, as was the case with this program, really is something very beneficial.

I strongly believe, as I'm sure all members of the committee do, that we have to prevent institutionalization, we have to prevent people from going to nursing homes and encourage options which allow them to stay in their homes as long as possible. The more that day care is available, the more that this goal becomes a reality.

My question is for whoever wants to answer it. Without a long-term program or a way of covering a lot of the cost of day care on a daily basis, I was just wondering—I know that to some extent this legislation tries through demonstration programs or through grants to the States, as Ms. Lombardo mentioned, to try to encourage not only research but also day care alternatives.

I was just wondering specifically how that could be done. When I went to the Our House Program, they had a problem not only in terms of getting the financing for the day care, which I think costs about \$35 or \$40 a day, and if you were under Medicaid, it was covered but if you weren't, you had to private pay, but also in terms of capital construction.

It seemed like there were two problems. On the one hand, there was the problem of covering the cost, which you would have to do privately if you weren't on Medicaid, and on the second hand, there was the fact that there wasn't, I guess, capital available to build or start these new programs.

I was just wondering to what extent we are addressing that. I know we are not necessarily addressing the cost or the reimbursement, but are we addressing the cost of trying to open these new day care centers by just providing money up front so that they can get going?

I don't know if Ms. Lombardo can answer that or anybody can, because I got the impression that that was just as much a problem as the actual coverage or reimbursement on a daily basis.

Ms. LOMBARDO. Well, you are right, and most of the existing day care programs are struggling. They have short-term funding. If they were lucky, they were able to make use of an existing space and just pay for modifications, but they had to get the money from somewhere and there is only so much demonstration money available in any State.

That is why we really need a long-term care insurance program, because you are not going to get the massive amounts of day care or in-home respite, which is equally as important, by the way, as day care. Not all patients can go out of the home. Sometimes it is just unacceptable.

Without the infusion of a general financing program for the country, we are not going to get the amount of respite and day care that we need in this country.

Mr. PALLONE. You mentioned that with this legislation that we would be encouraging Federal-State matching type programs. To what extent are the States getting involved in—I know New Jersey has started—but to what extent nationwide are States getting involved in trying to put the money up front for these new centers, for day care centers specifically?

Ms. LOMBARDO. This is one of the most popular programs in the States for Alzheimer's and other related disorders. As I mentioned, there are over 40 States now that are getting their feet wet. We don't have the exact count of the number that are getting into respite and day care but I'm guessing about 15 or 20.

I am proud to say that our State of Michigan, Mr. Schuette, is one of them. We have about \$400,000 a year going into Alzheimer's respite and day care programs. The State of California has a larger program, as do Florida, Ohio, New York, Illinois, New Jersey and others.

But again, as in Michigan, that funds six programs, what are six programs going to do for a population of millions?

Mr. PALLONE. There is a Federal demonstration program now?

Ms. LOMBARDO. Do you mean the Medicare demonstration?

Mr. PALLONE. Right.

Ms. LOMBARDO. Yes, and that will help fund day care and respite care at eight sites, which include, as Congresswoman Slaughter said, Monroe County in New York. But again, that is just eight cities, an average of 300 Alzheimer's patients each. It is, a start, a way of seeing if it can work.

Mr. PALLONE. Thank you.

Ms. LOMBARDO. You are welcome.

The CHAIRMAN. Thank you, Jerry. Ms. Morella.

Ms. MORELLA. Thanks again, Mr. Chairman. This is for Ms. Lombardo. You just touched on a topic that interests me and that is, what progress is being made by various States? Are you telling us, by virtue of what you said about Michigan and California, that you have an account of what progress each State has been making in this area?

Ms. LOMBARDO. We are having our first public policy forum in Washington the first week of April. As part of that, we are inviting State officials from all over the country to come and discuss innovative Alzheimer's programs around the country.

For that forum we are putting together a directory of as many of the existing Alzheimer's programs as we can find out about. That directory will help us answer some of the questions you have asked.

We do know many are establishing diagnostic and assessment centers. Also, several States are developing regulations for or looking at the concept of special care units.

I would like to mention that our association does have a guide booklet on what you should look for in a special care unit. The Directory of State Alzheimer's Programs will be printed by the end of the month. So any of the Members of Congress who would like to have this we would be glad to supply it.

Ms. MORELLA. I'm sure the committee members, Mr. Chairman, would like to. Didn't I ask that the way you wrote it down for me to ask?

Mr. Chairman, we may want to hold a hearing in this committee regarding what States are doing about long-term care as well as Alzheimer's. We might learn a lot from that.

Dr. WILLIAMS, if I could ask you, do you have any idea of the percentage of people in nursing homes who are there because of Alzheimer's or related disorders?

Dr. WILLIAMS. We have a general idea. There have been several different studies done on this question and invariably the number has run 50 to 70 percent of patients in nursing homes are there because of Alzheimer's or other dementias, of which the great majority would be Alzheimer's. So it is certainly at least half and probably higher in most.

I think that, in a way, relates partly to the question of specialized units. Since so many patients do have this condition in nursing homes, it would mean trying to be sure that essentially every nursing home was capable of caring for Alzheimer's patients, whether by special units or through general programs.

Ms. MORELLA. Just think, if you could find a cure for it, how you would be able to release all of those beds in nursing homes.

Are women more likely to have it because they live longer?

Dr. WILLIAMS. Yes, but not because of sex per se, not because of a gender difference that we know of, at any rate, in terms of the risks but just because more women live into very late years.

Ms. MORELLA. So it is related to age. Do you have instances of people who are significantly younger who also get it?

Dr. WILLIAMS. Yes, indeed. Unfortunately, I was presented with a patient a couple of weeks ago on rounds in our own dementia clinical unit whose disease began at age 45. That is very rare but it seemed to be unequivocal. There are a small but significant number in the 50's or 60's; however, it is mostly in much older people.

Ms. MORELLA. Thank you, and thank you, Mr. DeLay for coming and representing AARP. We always appreciate that.

Mr. Moll, Your testimony is a very moving account of your personal experience and the difficulty you had.

Mr. MOLL. Thank you.

Ms. MORELLA. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you. Ms. Slaughter.

Ms. SLAUGHTER. Thank you, Mr. Chairman. I had to leave for something that was previously scheduled and believe me, I hated to.

I've been through some of the same things myself with my own parents and I know that feeling, particularly when you said how lonely you were for your father when he was sitting next to you. That really struck a chord with me.

If I could ask a question of Dr. Williams, please. Dr. Williams, I am concerned about the problems and a lot of publicity that we have had lately about Alzheimer's patients continuing to drive. You know in New York State, for example, our drivers licenses are good for 4 years. Given what we know now, how often should the Alzheimer's patient be retested to maintain their drivers license?

Dr. WILLIAMS. This is an important issue, Congresswoman Slaughter. There are several recent studies just published this year showing unequivocally that there are increased instances of accidents by people who have Alzheimer's disease compared to age and sex-matched other people.

However, the problem isn't limited only to Alzheimer's victims. There are other people with other disabilities who are risky drivers as well. In my judgment, what we really need to achieve is—and this we need some research on—is to develop ways for adequately testing drivers so that we could have some confidence about who is a risky driver and who isn't.

I think this could be done much more than we do, for example, with simulator testing, and it should apply, in my view, to all drivers, or at least under certain conditions such testing would probably need to be repeated at least yearly, if there was any question of a dementing disorder, in order to have some confidence in the value of the tests.

This presents great difficulties because of the fact that many times only one member of an elderly married couple can drive. For people who are not living in reach of public transportation, if that spouse becomes demented or unable to drive, it means really total isolation.

This came up in a discussion in Albany at a day-long session on Alzheimer's disease that I was a part of just last week. One person speaking there, a physician, was saying that he knew of examples where the nonaffected spouse would coach the affected one while that one still drove. Now, that is kind of worrisome, but here is a couple who refused to give in and move or take some other drastic action to try to live differently.

What we really need is more research and rapid development of ways to appropriately assess drivers. Our institute is working with the Department of Transportation to encourage such research. They are very much concerned. It is a difficult problem, a very difficult problem, and yet, obviously, we need to do something about it.

Ms. MORELLA. Could I ask if this young lady would yield?

Ms. SLAUGHTER. Of course.

Ms. MORELLA. Thank you. You just put in a wonderful plug for continued funding for our Metro System. Thank you, Dr. Williams.

Ms. SLAUGHTER. Does this disease ever go into remission or have you ever seen any case of that or is it just progressive?

Dr. WILLIAMS. No. It may be very slowly progressive. I've seen, and it is well documented, that many people seem to maintain almost a plateau for years at times, but there is never a real remission back to normal.

Ms. SLAUGHTER. How do you account for that plateau? Do you have any idea at all?

Dr. WILLIAMS. We don't understand why it proceeds more rapidly in some people than others. There is a considerable variation in this. Generally speaking, it seems to be a more rapid course of disease in younger people than older, but that is not absolutely clear.

Ms. SLAUGHTER. I certainly thank all of you for what you have done here this morning. I had a long-term care hearing in my district and by far, the people who were caregivers for people with dementia would just ring your heart, people who would say they couldn't take a shower, they couldn't go to the bank, they couldn't do anything without someone coming in to take their place for just a few minutes. I don't think any of us really understand the magnitude of it. Thank you very much.

The CHAIRMAN. Thank you. Is there any other member of the committee that would have a question at this time?

Ms. UNSOELD. Thank you, Mr. Chairman. Dr. Williams, you mentioned that there may be a possible relationship between toxins, pesticides and Alzheimer's disease. Would you mind steering me to some of that information because I am very interested in the pesticide issue.

Dr. WILLIAMS. Let me say first, Congresswoman Unsoeld, that the best example we have of a toxin in the food chain causing a dementing disease was an epidemic in Guam—this was after World War II—in which many people there were affected by an explosive outbreak of Parkinson's disease and some other neurologic diseases, along with dementia.

With a lot of careful research, the cause has been traced almost certainly to a toxin that was in the food they ate during that period, the starchy food of a native plant which they used because they didn't have many other sources of food, and that almost certainly produced that particular epidemic of a dementing disease with other neurologic signs.

Using that as an example, there are some comparisons with Alzheimer's disease. People are very vigorously looking into the question of whether there could be something that we don't really suspect, that in some people, perhaps genetically predisposed people, might lead to the Alzheimer's changes. That is speculative to a degree, but is a very important area of research.

On the matter of pesticides, again, what we have are suggestions that dementia may be more common in areas where people have had long exposures to pesticides than in other areas, but that clearly needs more research. We have issued a program announcement, calling for more studies on the possible relation between pesticides and dementia. It is speculative, but worth pursuing.

The CHAIRMAN. Thank you. I think that today's hearing clearly shows that there is a great deal more to be done. I think that Mr. Moll was correct when he said that we are still in the Dark Ages when it comes to Alzheimer's. We are a long way from finding out what we can actually do.



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Before we leave, I would like to again impress upon each and every one of you the importance of passing the Alzheimer's legislation, that up to this time doesn't have a number. It will be introduced today and it will be given a number. Then we will make that number available, Ms. Lombardo, to your organization so the various locals throughout the country will know about it.

We will also make it available to you, Mr. Moll, because what I would like to see, really, is the Actors Guild, the Writers Guild, motion picture people actually involved in helping us do something about funding this disease.

With Mr. DeLay, I would like to also see his organization, with millions of people as members, and then together with the resources that are made available to Dr. Williams, the contacts that he has throughout the entire Nation, the professional people that he can meet, I would like to see a coalition of all of these resources.

In other words, using the principles of community organization to actually make possible a change in the Congress of the United States so that this piece of legislation can pass. The only way that that can be done, in my opinion, is to get these resources together.

So you see, when we asked you to come before this committee, we asked you not only to tell us about your experiences and give us your expert testimony, but we also wanted you here, at least I did, because I felt that I had to talk to you as individuals because of the resources that you have at your command, the people that you come in contact with almost on a daily basis, and what can be done if we work together to do something about Alzheimer's disease.

We don't have a number yet but we will get one. We will make it available to you. Let's see if together we can do something so that this year—not next year, not in this Congress, we want it this year—we can pass this legislation because it will benefit society as a whole.

I thank each and every one of you for your expert testimony. Thank you for taking your time to be present and helping this committee. We will, in turn, do everything we possibly can to promote your best interest.

Thank you very much. The hearing is adjourned.

[Whereupon, at 12:10 p.m., the hearing was adjourned.]

